Making Sense of Adult Life
A guide to transition for families of young people with special needs and disabilities in West Sussex

Reaching Families
2nd Edition
Making Sense of Adult Life

A guide to transition for families of young people aged 14+ with special needs and disabilities in West Sussex

Second Edition
November 2018
In memory of our much-loved chairman, Seb Trezise.
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In September 2014, the Children and Families Act made it a statutory obligation for local authorities to provide parents with information on SEND provision in their area via a website known as the ‘Local Offer’. This should be available to all families who have children with SEND aged from birth to 25 years and it must also be available in another format for families who don’t have access to the internet.

The Local Offer brings together information and services available in a given local authority area. To create their Local Offer, each local authority must talk to parent carers, as well as children and young people with SEND, to see what sort of services and support they need.

No information resource, whether online or printed, can be truly encyclopaedic. By definition the information landscape is constantly changing – services change shape and structure, new organisations are founded while others close.

This is why we believe that used together, our book and the Local Offer website complement each other brilliantly. Where you cannot find information in one we hope that you can find it in the other. The constantly changing landscape also means we will produce further editions of this book – to this end we have scheduled the third edition for publication in 2020.

We hope that by using Making Sense of Adult Life with the Local Offer, you will have the best support and information at your fingertips, so you can navigate your way through the transition years as smoothly as possible.

https://westsussex.local-offer.org
About Reaching Families

Reaching Families was established in 2008 by parent carers to ‘empower, care for and inform parents and families of children and young people with disabilities and special needs in West Sussex.’

The charity continues to be governed and managed by parent carers. We achieve our mission through delivery of a number of projects and services including:

- **Making Sense of It All** – a guide for parents of children with special needs in West Sussex aged 0-14.
- **Making Sense of Adult Life** – a guide to transition to adulthood for parents of young people with special needs and disabilities aged 14+.
- **Fact sheets** – we have published a series of fact sheets on childhood disabilities and other issues that combine clinical information with local information on relevant projects and services.
- **Training roadshow** – we deliver a variety of training workshops at various locations and venues across West Sussex. Subjects covered include: anxiety, challenging behaviour; DLA and benefits; getting support at school, sensory issues, sleep management; and stress and resilience.
- **Umbrellas** – we manage three support groups for parent carers of children who attend mainstream schools in Billingshurst, Littlehampton and Worthing.
- **Our Facebook group** – which has over 2,000 members, is a vital means of providing information and resources to parents and a useful forum for them to seek advice and support from other families.

For further information on Reaching Families please visit our website:

www.reachingfamilies.org.uk
Since 1978, Aldinbourne Trust has led the way in providing a roadmap for generations of families who have young people with SEND. It is one of many organisations founded by families of young people with disabilities, who wanted to provide great, real life opportunities, particularly as their sons and daughters were becoming young adults and leaving school.

During the past 40 years, Aldingbourne Trust has seen many changes and challenges in supporting young people into adulthood. Way back in 2001, many of us involved with people with learning disabilities were delighted to see the government produce *Valuing People*, a white paper that set out a range of values and aims to improve peoples’ lives. There was an air of change, of potential, of optimism, of opportunities.

The white paper talked about education, housing and employment and that everyone should have the same opportunities to live the life they wanted, something which was long overdue.

In 2006, the National Skills Council’s strategy, *Learning for Living and Work*, called for a radical change to enable young people with learning disabilities to progress to the maximum possible level of independence and activity in their communities and in employment.

However, in 2010 a working paper for the Department of Health Policy Research Programme highlighted that ‘for many disabled people, the process of moving from children’s to adult services is problematic’ [Soper et al] The paper identified problems in co-ordinating services, lack of multi-agency working, lack of
information for young people and parents, insufficient attention to the concern of the young person, and lack of appropriate services for people to move on to.

It was clear that there were still many problems in transition to adulthood. In 2014, the Children’s and Families Act renewed the focus on transition to adulthood for young people with SEND.

Local authorities now have a legal duty to set out how they will provide the support children and young people will need to prepare for adult life across education, health, social care and other relevant services, such as housing and employment support.

In the twenty years I have been at Aldingbourne, I have worked with many families from across the UK who want the best for their young people and have been on a quest to find ways to make it happen. Many have come to us by word of mouth. We connect families to share their experiences and wisdom. Everyone’s journey is different, but Making Sense of Adult Life is a reminder to families and people that there are many sources of information and support, and that talking to other families can be invaluable.

For people approaching adulthood it can be a tricky time. One young man’s parents started their search for support when he was in his early teens. There were some tentative, anxious faces. When he and his family were ready, it was time for him to move in to a shared flat and start his learning and working in a social enterprise. After his parents left, he sat quietly and a big tear ran down his cheek. It was a milestone moment, experienced by many a parent and young person when they leave home. Within days, however, this young man revealed his sense of humour, appetite for adventure and strong camaraderie. I have enjoyed spending time with him at music festivals, cooking groups and bumping into him in our town. He has a great life.

In 2016, the Aldingbourne Trust participated in a national survey on the impact of Valuing People. For transition, the lived experiences of individuals,
families and professionals highlighted similar themes to Soper’s research. Carers from across the UK also told us there are some improvements being achieved by the use of personal budgets, an emerging culture of participation and higher expectations for good housing and access to employment. These higher expectations are vital – we must keep raising the bar and expecting that people will experience life’s ups and downs, challenges and successes.

With diminishing public funding in relation to demand, there is a good case for investing in prevention and early support. As this guide goes to print, Aldingbourne Trust is opening our first accommodation in West Sussex specifically for people leaving home for the first time.

We are working in partnership with Chichester College and with some of the groups listed within to listen to young people and their families. We know people with SEND can – and do – live and develop in communities where they learn, work, have relationships and follow their interests – just as any young adult would expect. Ensuring early adult experiences are positive and that it is a time of exploration and adventure has a powerful, progressive impact on future outcomes for our young people.

I have the privilege of working alongside people with learning disabilities who work full-time, part-time, win employee awards, travel the length and breadth of the country, talk at conferences, recruit their own staff, parent their own children, support and care for their friends and families, exhibit and sell their artwork, run half-marathons, challenge stereotypes and live good lives.

I applaud the Reaching Families Team for publishing such an invaluable resource for young people with SEND and their families across West Sussex.

Sue Livett
Managing Director,
Aldingbourne Trust
Introduction

Reaching Families is delighted to present you with the second edition of *Making Sense of Adult Life*, our guide to transition to adulthood for parent carers of children with special educational needs and disabilities in West Sussex. It is immensely satisfying to do so on the tenth anniversary of our founding.

First published in March 2016, this title lead the way in providing information about transition to adulthood at a time when many organisations were still in the early stages of producing resources to help parent carers and young people to think about their future and what it may look like.

As a result, *Making Sense of Adult Life* has been as well received as our partner title *Making Sense of it All*, being welcomed by both parent carers and professionals alike, who have given us excellent feedback on the content. We were particularly delighted to find in an online survey of parent carers in November 2017 that 90 per cent would recommend it to other families.

*Making Sense of Adult Life* has a similar structure to our partner title and also uses accessible language. It has been thoroughly checked to ensure information is relevant and up to date. Chapters have also been reviewed by West Sussex professionals to ensure that parent carers have the best possible information and advice at their fingertips.

It is designed to be used as and when you need it; not exactly bedtime reading but a useful resource to reach for when you need further information or feel in doubt on a subject or issue.
We know from research and contact with parent carers across the county that transition to adulthood is a daunting time for young people and parents alike. The move from children’s to adult social services, from secondary to further education, or perhaps into training and/or employment, housing and independent living present a number of challenges for young people and their families, not least in accessing the information they need to successfully navigate their way into new and uncharted territory.

The recent local area Ofsted inspection, carried out in February 2018, whilst generally positive about the overall progress being made in West Sussex, did highlight the challenges we face in providing better support for young people with SEND as they make the transition to adult life, in particular the provision of more consistent and cohesive support from health and social care and help in securing and maintaining paid employment.

With challenges like those described above the value of information to parents cannot be understated. Knowing how and where to best access support for our children might not be half the battle we face but does give us a head start and those parents with the most know-how inevitably secure the most support.

We hope this new book will help parents in preparing their child for the journey into adulthood. The content is based on another guide researched and written by parent carers in Brighton. *Through the Next Maze* is published by Amaze, who we have long held in high esteem for their excellence in the delivery of services to the parent carer community. We have taken the content of *Through the Next Maze* and adapted it to a West Sussex audience.

Since the first edition of this book was published in 2016, Reaching Families has been working hard to deliver more support for families of young people with SEND including more workshops on issues that are pertinent to them and other information available in our series of fact sheets.
There are a number of people we would like to thank for their editorial contributions and feedback on this guide. In particular we would like to thank Sue McMillan, an editor and parent carer with more than 20 years’ experience in publishing; Helen Jervis for her hard work and tenacity in checking and updating the directories; and Charlie Rowlins for his excellent work designing the book and preparing it for print.

We would also like to thank the following people for their editorial contributions: Ann Blackburn, Tina Brownbill, Lindsey Butterfield, Garrett Craig, David Deane, Elizabeth Flegg, Karin Fuchs, Robert Hayes, Lucy Hughes, Aloisia Katsande, Erica Keegan, Jo Kenworthy, Richard Lamplough, Sue Livett, Heather McIntosh, Charlotte Moroney, Michael Rhodes-Kubiak, Liam Ryan, Rachel Sadler, Kate Scales, Mike S Smith, Sophie Spearman, Peter Stanley, Sarah Stirling, Ellen Tomlinson and Paul Woodcock.

Special thanks also goes to the four young people from West Sussex who are featured on the front and back covers: Sarah Bush; Sophie Oliver; Tom Speers; and Hannah Szczepanski.

Making Sense of Adult Life and Making Sense of It All are both available to parents free of charge. The books are available to order on our website (with a charge of £2.50 for postage and packing) or you can source them via schools or agencies within health and social care.

They are also available to download as e-books from our website in both iBook and Kindle format. For further information please visit: www.reachingfamilies.org.uk

Editor’s note: In this book, you will see that we have used the term ‘child’ interchangeably with ‘young person’. This has been done to avoid needless repetition and to make the text as accessible as possible. No matter how old our offspring are, they will always be our children, so we feel that it is still appropriate to use this term, even when your ‘child’ is an adult.
Planning for your child’s future

For parent carers of a child with special educational needs or a disability (SEND), thinking about the future can feel overwhelming. Picturing your child as an adult can be especially difficult if you do not know how their condition will progress, or how their needs may change.

However, early planning for your child’s future will help you to ensure that they get the support they will need as they reach adulthood and move from children’s to adult services. This is known as ‘transition planning’. Thinking about what your child needs and how this may change as they grow will help you to make sure that their transition goes as smoothly as possible.

The SEND Code of Practice 2015 says preparing for adulthood should cover the following:

- **Higher education and/or employment** – this includes exploring different employment options, such as support with becoming employed and help from supported employment agencies.
- **Independent living** – this means young people having choice, control and freedom over their lives and the support they have, their accommodation and living arrangements, including supported living.
- **Participating in society** – including having friends and supportive relationships, and participating in, and contributing to, the local community.
- **Being as healthy as possible** in adult life.

For more go to: www.preparingforadulthood.org.uk
This handbook will support you as you consider your child’s options as they begin their transition from childhood to adulthood.

**Recent changes to the SEN system**

From September 2014 there were some big changes to the SEN system. Statements of Special Educational Needs (SEN) were replaced by Education, Health and Care Plans (EHC Plans). Since then, the majority of children and young people with existing Statements of SEN have been transferred to EHC Plans.

The advantage of an EHC Plan is that it brings together all the support a child or young person needs (and is legally entitled to) in a single plan, which can last up until a young person is 25 years of age. The plan sets measurable outcomes. Some will be short-term, while others will look more to the future.

It was hoped that the changes to the SEN system in 2014 would help schools and colleges to be able to meet the majority of a young person’s individual needs through their own SEN support programmes.

As part of this, schools and colleges should include planning for effective transitions as part of their Individual Learning Plans or other record-keeping approaches, as this is key to the future success of young people with SEND. You can find out more about how your child’s school or college deals with transition planning by contacting them.

Whether your young person has an EHC Plan or is supported by their school or college, the aim should be the same: support should help a child’s development so that they achieve the best possible educational and other outcomes.

Therefore, if you or your young person decide that they need additional help over and above that offered by the school or college’s SEN support programme they will be able to request an EHC Needs Assessment.

Getting an EHC Plan can be very helpful, as it may enable your
child to receive support with their education up to the age of 25, if they need it. You can find out more about EHC Needs Assessments at IPSEA: www.ipsea.org.uk/what-you-need-to-know/ehc-needs-assessments.

**Transition planning: what to expect**

The Children and Families Act 2014 states that the Local Authority ‘must set out how they will provide the support children and young people will need to prepare for adult life across education, health, social care and other relevant services, such as housing and employment support."

When your child turns 14 (usually in Year 9) every annual review should include a focus on preparing for adulthood. For health services this will require them to plan an effective transition from specialist paediatric services to adult health care and support young people to understand how services will support them as adults, ensuring those professionals understand the young person’s needs and put in place the appropriate services.’

Taken from the Council for Disabled Children: www.councilfordisabledchildren.org.uk

You can find out more about what to expect in a government document called the *SEND Code of Practice 2015*. The *Code of Practice* provides guidance about how children and young people with SEND should be supported. To view the *SEND Code of Practice* go to: www.gov.uk/government/publications/send-code-of-practice-0-to-25.

**Preparing for transition planning**

There are plenty of things you can do to get the most out of transition planning in Year 9 and in the future.

**General planning**

You’ll get much more out of transition planning if you understand some of the options that may be available to your child, so it pays to spend some time finding out what’s on offer.

The focus now is very much on the child, so their views and
aspirations should be at the centre of transition planning.

It is important, therefore, that you prepare your child so they can contribute as much as is possible. If you can, you should talk to your child about what they would like to do post-16, and also look at their options looking further ahead into adulthood.

If your child has communication or learning difficulties, it is still important to take their views into account. You will find plenty of suggestions to help you get a clearer idea of their hopes and preferences in the next chapter, *Involving your child*. For example, if your child has a social worker, local Advocacy Services (see pages 30 and 36) may be able to support them to communicate their ideas to professionals.

You should also consider talking to other parents, school staff or, if your child is at mainstream school, the school Special Educational Needs and Disabilities Coordinator (SENDCo) can give you a range of information.

School staff should be able to tell you about School Leaver Programmes and alternative Key Stage 4 (Year 10 and 11) provision for young people with special educational needs. Schools may have strong links with local further education providers and may provide pupils at Key Stage 4 with work experience programmes that run alongside GCSEs, or are an alternative to them. The school will usually provide careers advice and guidance for students from Year 9 onwards.

**Questions to ask yourself**

These are some of the questions you might want to ask yourself in preparation for transition planning. You may want to make a note of the relevant ones so you can take them to the annual review meeting.

- Does your child have any thoughts or ideas about what they will do when they leave school? What would you like them to do?
- Has your child got a school record of achievement or
equivalent? Looking over this may help you to think about their strengths and future direction.

- What have other children from the school gone on to do?
- What type of social activities does your child enjoy?
- What courses are offered by local colleges and how could your young person be included in their local community?
- Are there courses offered by colleges further from home that may be more appropriate for your young person?
- If you’re thinking about a residential college, how could it be funded?
- If your child would prefer to be working, can you find out about apprenticeships, training and employment schemes that can offer support?
- Will your child live at home with you or move to independent or supported living when they leave school?
- If your child stays at home, will you need a break and if so, how often? How can this be organised and funded?
- What daytime activities are available locally? Would this type of provision suit your child?
- Does your child have health needs? How will health care provision like speech and language therapy, occupational therapy or physiotherapy be arranged?
- Does your child need specialist equipment? If so, who will provide and maintain it?
- What about transport? How will your child get to a college course or apprenticeship and social activities? Will they need support to do so?
- What about benefits? Are you and your child getting all the benefits you’re entitled to?
- Is your young person eligible for a 16-19 year old bursary to help with costs like transport, food and equipment?
- Do you know how benefits are affected by college or part-time work? Do you know how your entitlement to benefits will change if your child claims benefits as an adult?

‘I knew what I wanted to do from quite an early stage but I needed to know how to get there.’ (Sarah, 18)
First steps: The Year 9 annual review

Parent carers whose child has an Educational Health Care Plan (EHC Plan) will already be familiar with the annual review process at school. However, the Year 9 annual review is slightly different.

The review will cover the same things as before – your child’s EHC Plan will be looked at as usual, the same issues will be considered and the same timescales apply. But the meeting will also focus on transition planning – the beginning of preparations for adulthood – so it will cover a far broader range of subjects than you’ll be used to. It may sound overwhelming, but it is just the first step in a process that will take several years.

For the Year 9 annual review, you and your child will be asked to think about their future and, with the input of the professionals involved with your child, a plan of action will be put together.

If your child has an EHC plan, the transition planning will be written into the plan, so it should be updated at each review, clearly stating the actions that need to be taken, the responsibilities of everyone involved and timescales for all the actions.

Young people are now expected to stay in some form of education or training until they are 18. This is called ‘Raising the Participation Age’ (RPA). This means that it is no longer an option to leave school at 16 and get a full-time job, unless training is also undertaken. So, looking at how your child will continue their post-16 education will be a key part of transition planning.

In addition to further education, vocational training and employment, the transition process should cover your child’s health, leisure activities and where he or she may live as an adult.

In West Sussex, advice and guidance is delivered through the school setting and, when your child reaches their year of transfer (Year 11 upwards), a Senior Planning Coordinator from the Local Authority will also be
involved. Schools can also access careers advice and guidance from the West Sussex Skills Business and Enterprise Team.

You can also get advice from West Sussex SENDIAS. It has Young People Advisers, who can support young people up to the age of 25 and help them to think through their options. For more details, contact their helpline: 03302 228 555, or email: send.ias@westsussex.gov.uk (parent carers) or cyp.sendias@westsussex.gov.uk (children and young people).

**You and your child at the centre of planning**

The government says disabled young people should have ‘person-centred’ transition plans, which clearly state the support they’ll need once they leave school.

A person-centred approach encourages participation from the young person, parents and everyone attending the transition planning meeting. It also means that information should be brought to the meeting in a way your child can understand, so this may include photographs, symbols or pictures, for example.

Everyone involved in supporting you and your child to prepare for the future should take a person-centred approach to annual reviews. Meetings should be interactive and less formal than traditional annual review meetings to ensure that you and your child are central to the whole process.

The aims of a person-centred approach to the Year 9 transition review meeting:

- To identify and discuss your child’s strengths – what they’re good at, what people like and admire about them – because whatever they do in the future should build on their strengths.
- To identify what is important to your child (now and in the future) and the help and support they need.
- To identify what needs to happen to keep your child as healthy and safe as possible.
- To identify and discuss what is
going well and what isn’t going well from the young person’s and their parents’ perspective, as well as from the perspective of school staff and others attending the meeting.

- To agree actions that support your child to get what is important to them now and in the future, continue what is going well and change what isn’t going well; and try to resolve any ongoing issues.

**Tips to help you prepare**

- Check if your child’s school is familiar with a person-centred approach to transition review meetings. If they’re not and you’d like them to use this approach, ask the school in advance. If you need help with this you can contact West Sussex SENDIAS, see page 18 for details.

- Some schools are doing preparation with young people before their Year 9 transition review meeting. Ask if this is happening at your child’s school.

- Discuss the topics with your child well in advance of the meeting so you can help them to prepare and you know what they might want to happen next.

- Think about the aims of the person-centred transition review before the meeting so both you and your child come prepared.

- It can be helpful to write down the things you want to talk about beforehand, so that you and your child have a checklist of points to cover during the meeting.

**What to expect**

These are some of the things you should expect in a transition review:

- The head teacher or another member of staff, usually the Special Educational Needs and Disabilities Coordinator (SENDCo), is responsible for ensuring that the Year 9 annual review is organised as a transition-planning meeting. They will send out invitations, sort out times and dates and gather together any relevant reports and advice.
• They must invite: the parents; the young person; your Senior Planning Coordinator from the Local Authority; a representative from social care (social worker); and anyone else the head teacher or the Local Authority suggests.

• Most people invited to the Year 9 annual review don’t have to attend. They can opt to send written reports or advice to the review instead. But in practice they don’t have to do either. A social worker should come if your child’s likely to need social care support after they leave school, or if they’re ‘looked after’ by the Local Authority.

• To prepare for a Year 9 annual review, the Local Authority has a legal obligation to check with social care whether the child is disabled. Children and young people with EHC Plans are considered disabled and are protected under the new legislation. You might not have had contact with social care before, but some support services may be useful to your child as they become an adult, so this might be a good time to ask for a social care assessment for your child if you have not done this before.

• The Year 9 annual review paperwork follows the Department for Education’s ‘Preparing for Adulthood pathways’. You can find out more about this at www.preparingforadulthood.org.uk, or by searching on the Local Offer (see page 4 for more information). You can also download the Preparing for Adulthood Information Pack from: www.sendpathfinder.co.uk/preparing-for-adulthood-information-pack.

• The school will write up your child’s annual review report. If he or she has an EHC Plan the planning for adulthood may be taken into the plan, as it has a focus on future goals and outcomes.

**Key professionals involved in transition planning**

**Senior Planning Coordinator**

In West Sussex, the Senior Planning Coordinator should be invited to the Year 11 annual
review and also the Year 12 and 13 reviews if your young person is leaving school or college.

The Senior Planning Coordinator may attend subsequent reviews as appropriate. They may also stay involved when the young person leaves school to attend further education or training.

**Social Care**

If a young person is already known to Children’s Services, referrals are made to equivalent teams within Adult Services to see if they will provide support once the young person is over 18.

**Young People Advisors**

Young people can get information about colleges and courses that might be suitable for them from West Sussex SEND IAS’s Young People Advisors. If your child wants to do a particular college course after they are 16, they can also ask the YP Adviser to look into whether their Year 10 and 11 subject options will give them the qualifications they need. For contact details, see page 18.

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**Tips for the year 9 annual review**

**Before the meeting**

- Remember that, along with planning for the future, your child’s EHC Plan will be reviewed and may be amended. Read through your child’s EHC Plan to see whether it needs amending. If it does, flag it up with the school and casework officer and ask them to get any assessments or advice that supports the amendment before the annual review meeting.

- If you need advice, contact West Sussex SENDIAS on their helpline or by emailing them (see page 18).

- If your child hasn’t had an assessment from an Educational Psychologist (EP) in the past couple of years, it might be worth requesting one before the meeting to make sure all their special educational needs have been clearly identified. Make sure significant needs like speech and language therapy don’t slip out of the EHC Plan.

Changes to the EHC Plan
are decided by the Local Authority, but you have the right to appeal them.
• Identify who your child’s Senior Planning Coordinator is and, if they’re currently receive social care, ask who will support your child’s transition to adult social care. It pays to establish a relationship early on so you can ask for support if you need it later.
• If you think there’s a professional involved with your child (such as from health services) who should be invited to the meeting, make sure the head teacher or SENDCo knows well in advance so there’s time to invite them to submit information or attend the meeting.
• For some of us, although we want our children to continue learning, it feels unrealistic to talk about career choices. Our focus is more on the need to arrange support for our child in the future, such as short breaks or supported living. If this is the case, make sure someone from social care has been invited to the meeting and will be attending.
• In theory, reports about your child should be circulated to everyone who’s planning to attend at least two weeks in advance. In practice, this hardly ever happens, so it’s worth asking the school to chase the professionals involved or do so yourself.
• We suggest you take someone with you to support you too, such as a friend or family member, or you could ask for a representative from West Sussex SENDIAS to come with you (see page 18 for contact details). If your child is coming to the meeting, is there someone they’d like to have there to support them, like a friend, advocate or mentor?
• Make sure you inform the school in advance if you intend to bring someone with you to support you or your child.
• Meetings can feel difficult. Reaching Families has produced a fact sheet called ‘Meetings and paperwork’ with hints about how to get the most out of them. You can find a copy on our website: www.reachingfamilies.org.uk/factsheets.htm.
West Sussex SENDIAS has also produced an information leaflet to help parent carers with annual reviews (see page 18 for contact details).

At the meeting

- Be aware that people at the meeting may not have any previous knowledge of your child, so you may need to fill them in.
- Ask what each of the services represented at the meeting can offer and what the planning process will be.
- Be clear about your child’s strengths and the support they need.

After the meeting

Annual reviews for EHC Plans continue until the young person leaves school. Transition Planning will be discussed at future annual reviews and after each one the EHC Plan will be added to and changed as needed.

The school must prepare a report on the annual review and send copies of this to: the parents; the Local Authority; the head teacher; anyone else who attended or provided advice and/or reports for the review; plus anyone else that the Local Authority feels is appropriate.

If you disagree with the content of an EHC Plan, you have the right to appeal to the Special Educational Needs and Disability Tribunal (SENDIST). Until recently, appeals could only deal with education matters. However, as of April 2018, a two-year national trial has begun to extend the power of the tribunal, so it will be able to make non-binding recommendations on the health and social care aspects of EHC Plans.

If you need help with an appeal, you can contact West Sussex SENDIAS, see page 18 for details). You can also ask for advice from IPSEA, see page 25 for details.

Constantly evolving

What’s agreed in the Year 9 annual review is the beginning of a long journey and decisions
are not cast in stone. While some young people know what they want to do after school, for others it will be a matter of waiting to see how they get on. It’s not always possible to decide early on and new options may present themselves further down the line.

Some of us have also been surprised by how much our children have flourished and grown over the years and have been able to consider a much wider range of opportunities than we would have thought possible when they were younger.

Some young people with more complex needs will keep an EHC Plan up to 25. The Senior Planning Coordinator will help to ensure that the EHC Plan is updated and relevant to the support they need at college. This should include active input from you and your child.

**Information resources**

Locally, as well as getting information and advice from West Sussex SENDIAS, families can also attend *Reaching Families’* training roadshow, ‘Making Sense of Transition to Adulthood’. For more, go to: www.reachingfamilies.org.uk/training.htm. **West Sussex Parent Carer Forum** also runs an information, advice and support fair entitled ‘First Steps to Adulthood’. For more, go to: www.wspcf.org.uk or check their Facebook page for dates.

Many national organisations also offer information and resources about transition. The British Institute of Learning Disabilities (BILD) has an easy-read section for people with learning disabilities and resources for families. See: www.bild.org.uk.

**Cerebra** has fact sheets and a parent guide to transition. See: www.cerebra.org.uk.

The **Choice Forum** is an online community for people with learning disabilities and their families where all sorts of topics can be discussed. There is an easy-read guide to staying safe on the forum. For more, go to: www.choiceforum.org.
Contact has resources to help families during transition. See: https://contact.org.uk/advice-and-support/your-child-your-family/moving-into-adulthood.

The Council for Disabled Children created the ‘Transition Information Network’, providing online resources, publications and events. It also publishes a free magazine entitled My Future Choices. Go to: https://councilfordisabledchildren.org.uk/transition-information-network. You can also access their ‘Into Adulthood’ resource hub with resources such as fact sheets, toolkits, and information about case law and legislation updates. Go to: https://councilfordisabledchildren.org.uk/our-work/adulthood.

Dimensions works with people with autism, challenging behaviour, complex needs and learning disabilities. The website has resources for families and young people, including a transition guide and other easy read guides: www.dimensions-uk.org/what-we-do/transition.

The Down’s Syndrome Association has a section entitled ‘Planning for Adulthood’ and an easy-read leaflet called ‘Listen to Me’. To find out more go to: www.downs-syndrome.org.uk/for-families-and-carers/teenagers-and-young-adults/planning-for-adulthood.


For advice and model letters on SEND law and education, you can refer to IPSEA’s section for young people aged 16 to 25 years. www.ipsea.org.uk/pages/category/young-people-aged-16-25. There is a separate section giving advice on transport to school or college for over 16s, see: www.ipsea.org.uk/pages/category/transport-to-school-or-college.

Mencap has a section on transition to adulthood at:
www.mencap.org.uk/advice-and-support/children-and-young-people/education-support/transition-adult-services, with links to other websites such as the British Association for Supported Employment (www.base-uk.org) and the Care and Support Alliance (www.careandsupportalliance.com).

The National Autistic Society also has comprehensive transition advice and a free transition support service for young people with autism aged 14+. For more, go to: www.autism.org.uk/transition.

You can find the full National Institute for Health and Care Excellence (NICE) guidelines on transition to adult health and care services at: www.nice.org.uk/guidance/ng43/evidence/full-guideline-pdf-2360240173.

The NHS website has a section on transition to adult health and care services, with useful information and links. Go to: www.nhs.uk/conditions/social-care-and-support/transition-planning-disabled-young-people.

Preparing for Adulthood is funded by the Department for Education to support local authorities, but families may also find it useful: www.preparingforadulthood.org.uk.

Scope has a section on its website that offers transition advice to parent carers and teachers. It also has an online community, where members can get support and advice. For more, go to: www.scope.org.uk/transition.

SOS SEN has information and runs workshops and events on post-16 options. You can find out more at: www.sossen.org.uk.

Together for Short Lives works with families of children and young people with life-shortening and life-threatening conditions. It has a transition to adult services hub, which can be accessed at: www.togetherforshortlives.org.uk/changing-lives/developing-services/transition-adult-services.
2 Involving your child

Parent carers are used to making decisions on behalf of their child to try to ensure that their needs are met. Over the years, you will have had to make many important choices for your child and will probably have felt comfortable doing so. This may have involved fighting hard to secure the additional support or specialist services that your child needs.

It is a huge responsibility and, even though your child is now moving into adulthood, the pressure to do the right thing by him or her remains. For some parent carers, therefore, the idea of involving their young person in decision-making may feel quite daunting, especially as we all want the best for our children and don’t want them to make choices that they may later regret.

However, all young people know what they like and don’t like and they may have their own strong opinions about their future.

It can be hard to put aside our own hopes and expectations for them, but it’s important to remember that plans that take their wishes and feelings into account are more likely to work.

Although there may be a huge variation in our children’s ability to make decisions, the information in this chapter is relevant to all families, including parents who may feel that their teenager has a limited ability to express their views. Most young people can show both positive and negative preferences to a person, a place or an activity and this ability can be invaluable when making decisions.

Some young people may use sign-language, visual symbols or other augmented or alternative forms of communication, but for simplicity, the terms ‘she tells us’ or ‘he says’ will be used to cover all methods of communication.
In our experience, a young person’s views are likely to be given greater weight if they communicate directly with those involved in the decision-making process, but they will need your support to do so.

This chapter will suggest ways in which you can involve your child in the decision-making process, as well as making sure his or her wishes are heard during transition planning. It also provides information on some of the rights you and your child have in the eyes of the law.

**Choices for our children**

Every parent wants their child to make good decisions that lead to them being happy and fulfilled in life. One of the things that concerns many parent carers about encouraging young people to have a say is that we want to make sure that they understand their options and what the outcomes of each choice may be.

However, the views of children and young people can be overlooked. This is especially true for disabled children who, after years of decisions being made for them, may feel that they don’t have a voice or that their opinion is not as important as those of other people.

‘You get talked about by everyone: “where shall we sit him... what time does he go to bed?” in front of you. You really believe you aren’t as much of a person as everyone else. You’d never think of having a say.’ (Jack, 16)

The balance between involving your child and fulfilling your role as a parent and protecting their best interests can seem a difficult one. But at 16, they’ll legally have the right to make their own decisions, according to their ‘mental capacity’ and at 18 they’re legally adults. It’s part of our job as parents to help them prepare for this during their teens.

Worries about their vulnerability as adults can stop us encouraging young people to get used to making some choices and decisions, but we will make them less vulnerable if we teach them that they have a right to be listened to and that their views should be taken seriously.
What the law says

It is a good idea to familiarise yourself with the laws protecting your child’s rights around decision-making. These are: the Mental Capacity Act 2005; the Equality Act 2010; the Human Rights Act 1998; and the United Nations Convention on the Rights of Persons with Disabilities 2008.

The Mental Capacity Act 2005

Parents have responsibility for decision-making for their children but, once they reach 16 years of age, the law says young people have the right to make decisions for themselves, wherever possible. The Mental Capacity Act 2005 covers a person’s ‘mental capacity’ – in other words their ability to make decisions for themselves and what to do if it is established that a person does not have mental capacity.

The act aims to protect and empower people who may not be able to make their own decisions. It also helps parents or carers understand how and when they can act on behalf of someone who may not be able to make decisions for themselves. It outlines how to decide if someone has capacity to make a decision and, if it is felt that they are unable to do so, it explains how decisions should be made for them and who should be involved in this.

The Mental Capacity Act covers major decisions including: property and financial affairs; healthcare and treatment; where a person lives; and decisions about everyday life such as personal care. Some activities or decisions need more capacity than others, but very few people are unable to make any decisions, even those with severe or profound and multiple learning disabilities and high support needs.

If people have ‘mental capacity’, they’ve the right to make their own decisions, whether others agree with those choices or not. This means that although you may disagree with a choice your young person has made, you cannot use this to argue that he or she does not have capacity.

Involving your child
If someone doesn’t have the capacity to make a particular decision for his or herself, the Mental Capacity Act makes it clear who can act on their behalf and how they should go about it. This is not necessarily you as their parent, although the act says that parents and family should be involved. For example, you might become their appointee to look after their welfare benefits, but a healthcare professional might be the decision-maker for them over a health issue.

The law also states that all possible steps must be taken to help people make decisions about their lives. It explains how capacity should be assessed to decide whether a person is able to make a particular decision at a particular time, and provides a Code of Practice for someone acting on their behalf. Decisions made for the person must be in their best interests and should place the least restriction on their basic rights and freedoms.

If you want to find out more about the Mental Capacity Act, visit www.publicguardian.gov.uk where you will find some free information booklets aimed at families.

Several other organisations can also help. Hft (previously Home Farm Trust) has produced a guide for carers called *Using the Mental Capacity Act*, which is available on their website: www.hft.org.uk, or call 0117 906 1700 and ask for a copy to be sent to you. Mencap has a resource pack aimed at parents of young people with more severe learning disabilities, which you can download free from www.mencap.org.uk or call 0808 808 1111 and ask for a copy. The Foundation for People with Learning Disabilities’s guide, ‘Thinking Ahead’ (see page 25) also covers the Mental Capacity Act.

Help is also available from the charity POhWER, a charity that provides support and advocacy services with regard to mental capacity in West Sussex. See: www.pohwer.net/in-your-area/where-you-live/west-sussex or call 0300 456 2370.

These two acts support our children’s rights to respect, choice and independence in their adult lives. The Equality Act 2010 aims to prevent discrimination on the grounds of age, disability, gender, race, religion, sexual orientation or transgender status. It replaces the Disability Discrimination Act 1995 and covers employment, education, public and private services, transport and more.

The Human Rights Act 1998 brought the European Convention on Human rights into UK law. Its key principles include the right to liberty, a family life and freedom of expression. If you want to find out more, visit the Equality and Human Rights Commission (EHRC) website: www.equalityhumanrights.com.

The Equality Advisory Support Service (EASS) also has an advice and guidance section on their website at: www.equalityadvisoryservice.com. You can also call their helpline on 0808 800 0082.

Helping your child to make choices

‘The consultant spoke to me, not my carer, and I told him the problems I had with the medication, and together we sorted it out.’ (Sarah, 18)

Most of our young people will be asked to make decisions about what they want to do and the sort of help they need as they move into adulthood. Some of our young people will be able to make these decisions for themselves, while others may need considerable support, especially for decisions with far-reaching consequences.

Involving children in decision-making is made much easier if they are already used to making choices and know that both they and their views matter.

You may find that you have to remind others dealing with your child that their views count. Whenever other people are communicating with your child make sure that they are given the chance to express their own opinions and preferences and
that these are taken seriously by the other person. If your child knows that their views are valued and important in everyday life, this will build their confidence and help them to make their voice heard in important meetings.

‘It’s hard to make choices... if people ignore you and don’t even try to find out what you want. They talk about you as if you aren’t there.’ (Andrea, 17)

Building decision-making skills

You can build your child’s confidence to help them make big decisions by giving them plenty of practise making smaller, everyday ones. As a parent, you can create opportunities for your child to practise ‘having a say’.

It can be useful to break things down into smaller steps. For instance, to help your young person to choose from a long menu it might be more manageable if certain items are ruled out, so you might say, “You’re not keen on pasta.” Choices about clothes to buy can be made easier if you give extra information: “Laces are tricky.”

If your young person is choosing what to wear you can help: “It will be very cold today.”

Similarly, when it comes to transition the first step towards deciding which further education course to choose could be: ‘What full-time courses are running?’ If the choices still seem confusing to your young person, you can help them by narrowing the options further.

‘Dan couldn’t decide which DVD to watch so I said, “Would it help if I gave you three to choose from?”’

If you do limit options, be careful not to do so for your convenience, or present them so the young person chooses what is going to please you or others, rather than themselves. Remember, it’s not just what you say, but how you say it and what your body language suggests.

‘Alice picks up on the intonation of my voice and even the order I present choices in. A lot of her speech is echolalic so I don’t offer what I think will be her preferred choice last. It’s about sounding interested without cueing her decision.’
Talking about the practical things children need – like someone to keep an eye on them, or a gluten-free diet because of their allergies – can be a helpful way to practise the decision-making process because it shows them the thinking behind making choices. This is a useful skill to learn for negotiating in more formal review meetings.

It is also important to check that your child has really understood what you are discussing so try to find ways to practise this.

‘I say, “Can you tell me what you think is going to happen?” or, “Could you tell Dad what we talked about?” That way Michael has the job of explaining it to someone else.’

**Tips for building decision-making skills**

- Present a choice broken down into small, manageable steps.
- Check the choice has been understood.
- Group different options together by an important common factor. So, for example, if you’re planning a day out, you might group several food options together or group together options for getting there.
- Remember to congratulate the young person on successful decision-making. Saying, “That’s a good choice!” conveys your pride in their ability to choose, as well as confirming that a decision has been made.

**Putting young people in the picture**

It can be hard for young people to imagine what it might be like to do something they haven’t tried before, whether it’s something small like a new food, or something bigger like a work placement. Pictures and photographs can help them. For instance, looking through magazines could help them decide what haircut might suit them or what colour scheme they’d prefer for their room. But the best experience, of course, is the real thing:
‘Jack wanted to paint his room red. I asked, “What sort of red?” and he said, “Like Christmas.” I took him to a friend’s house because her sitting room is red. He said, “It’s very hot and busy. I want a quiet room.” So we looked at the charts again and abandoned red!’

This parent was prepared to go along with her son’s decision to paint his room red. When your young person is making decisions it is important to remember and accept their choices even if it is not the decision you had hoped they would make.

**Dealing with anxieties**

‘I thought we’d talked about everything, but still David refused to stay for the sleepover. I asked what else there was to worry about and he asked how he would know it was his turn in the bathroom. It just hadn’t occurred to me. Once I knew, I could help him sort it out, but it was ages before he told me.’

Sometimes our own worries are communicated to the young person without us realising. For example, our fears about their safety may contribute to a child’s anxieties about new situations.

‘Chloe’s friends all hang about in town Saturdays and, of course, Alice wants to go. I was really worried about what would happen if she got separated from the crowd. Could I trust her sister to look out for her? I kept saying what if this... what if that... In the end I realised the arguments were making us both miserable and she said I was treating her like a baby. We got her a mobile and put in our home number. She promised to ring me if she got lost and we’ve practised who is safe to ask for help. I have to start trusting her because she starts college next year. Of course I still worry, but I try not to let it show.’

**Tips for coping with worries**

- Unpicking worries can take time, especially if it’s something that doesn’t make much sense to us. It’s important to take all worries seriously; they arouse strong feelings and can get in the way of trying new things or making choices.
- Consider the potential risks and build in safeguards. In this way the young person can take another step towards independence.
Under pressure

Young people rarely make decisions they’re happy with if they feel rushed, under pressure, or they are unable to give their whole attention. Sometimes they’re too interested in the TV, bored, tired, or feeling unwell. Some places aren’t good either; perhaps the shop’s too crowded, the sales staff too persistent or the music too loud. If it’s hard to hear yourself think, a young person may choose anything just to avoid the pressure.

‘Tom came back with a CD he didn’t want. The shop didn’t have more until Tuesday but the man said, “This one is just as good”. Of course it wasn’t, it didn’t have the right tracks and Tom was very cross. He seems very able, but we hadn’t appreciated that he hadn’t learned to say, “No thank you, I only want to buy...” After that we did some role play and practised being assertive. I remember we had a lot of fun taking turns doing the hard sell and standing firm.’

Choices as a family

Making decisions as a family can help a young person to learn about fairness, considering the views and feelings of others, and living with majority decisions. Finding out that it’s fair for everyone to have a chance to say what they think, that it’s okay to have different ideas and to change your mind as a result of hearing what others think is useful learning. It’s also helpful to discover that sometimes you don’t get your choice and have to compromise. These realities can be hard to accept, but it makes more sense to young people if pros and cons are discussed openly.

‘Mealtimes, around the table with everyone, that’s when we talk about big things like holidays. My priority is not too hot, Sam always wants a sandy beach and Jane wants her own tent this year. I needed to know that if she was to have a tent, she could take responsibility for her own space. We agreed that if she kept her room tidy from now on, she would have a tent of her own. Later we sat down and thought about keeping her room tidy, dirty washing, hoovering and finding a home for all the cuddlies.’

Tips for talking it through

- Negotiate a good time and place to think about important things.
• Remember, choosing to take more time to think about things is a decision as well.
• Make sure that you do plenty of ‘thinking out loud’ to show how you make decisions and solve problems.
• Remember, the consequences of a choice can be better understood by talking it through carefully. It’s important that your child understands that having the right to choose also comes with responsibilities.

Getting outside help

Many children choose to talk over serious decisions with their parents or other adults they are close to. But sometimes they may prefer to talk with someone who is outside their circle of family and friends. In some cases, they may also prefer it if this person is the one to support them in meetings.

The Advocacy Service can help disabled children and young people be heard. Advocates can go to meetings with a young person, help them to make a complaint or get legal advice. For more information go to: www.westsussex.gov.uk/education-children-and-families/your-space/life/advocacy/ or call: 03302 228 686.

For young people with mental health challenges, MIND have advocacy workers who can provide support to young people aged 11 to 18 living in West Sussex. For more information go to: www.mindcharity.co.uk/services/services-in-west-sussex/advocacy/young-peoples-advocacy/ or call: 01273 666950.

‘There were lots of things I didn’t like, and I kept getting into trouble. Mum kept telling them but nothing changed. Sometimes I shouted at Mum, “You didn’t tell them!” Then she said, “Well, you tell them yourself.” A lady came and helped me think how to say what was going on and she came with me in case I got stuck. Then everyone listened. At the end of the meeting [my teacher] said she would tell the other teachers to read my plan and do it and I said I would sit away from the noisy boys. My mum said I did a good job.’ (Ben, 16)
Involving young people in transition planning

It is worth taking time to prepare for review meetings. Your young person may find it helpful to look at some of the resources that we linked to in Chapter 1 – see pages 24 to 26 – the easy-read guides may be a useful starting point for discussion without feeling overwhelming.

However, it’s worth remembering that your child may need a period of time to look at the information and to think things through, so make sure you plan sufficient time for this rather than leaving it until the week of their review. Your child will be best able to contribute if he or she has been given sufficient time to consider their wishes and feelings, go through their options and prepare what they want to say.

It’s also worth doing this as some professionals struggle with empowering young people to make decisions on their own and also with taking into account their parents’ views. And sometimes they don’t attempt to find out what young people who have got complex communication needs are thinking.

Your child may be the star of the show at a person-centred transition review, but if they have a more traditional review, they may not be invited to all of it. Even if they won’t be there though, you can still find out their views and put across how they feel at the meeting. We assume below that they will be present – but you’ll find many of the points are still relevant if they’re not there for the whole meeting and you’re expressing their views for them.

Helping your child to plan for a meeting doesn’t have to happen formally. Sometimes it’s more productive to do five or ten minutes thinking a day over several weeks, rather than attempting longer sessions. And it’s always more manageable to ask one question at a time.

‘Oliver’s really good at the whole education side of things, because he likes learning, so he’s interested in talking about what he wants to do next, what he’d like to try.’
If it’s possible, avoid closed questions such as, ‘Do you like that?’ as it invites only a ‘yes’ or ‘no’ answer. It is better to ask open questions like, ‘What do you like about that?’ as this will allow your child to give a fuller response.

Repeat back what you think your child is telling you, to check that you’ve understood them. Avoid assuming what’s important to them. If it’s not easy to be sure what they mean, acknowledge you’ve got lost and start again rather than trying to keep going when you’ve lost the thread.

Be patient and resist the urge to fill silences or finish sentences. Let your child know there are no right or wrong answers and you won’t be cross with whatever they want to say.

‘Sometimes I’m not sure what Alice means, so I say, “Did you mean this, that, or something else?” and I sign the choices. She uses the sign for ‘different’ for something else.’

Of course talking and writing are not the only means of communication. If a child can’t speak, we should not assume that they don’t have views and preferences. Encourage your child to choose how they want to record their views. Think about using photographs, drawings, audio or DVDs as well as observation to ‘catch and record’ their wishes and feelings. Simple questions in word, sign, symbol or pictures can help many young people make sense of things and make their contribution.

Tips to help you prepare

- Check your child knows what the meeting is about, who will be there and what sort of things they may say. If you aren’t sure yourself, you’ll need to find out.
- Make time to talk with your child about any changes in their circumstances, their needs and your needs.
- Take a fresh look at their EHC Plan as there may be things that need updating.
- It is easy to unwittingly build value judgements into questions by asking your child ‘why?’ Try instead to say things like ‘tell me more’.
about that’. Ask more open questions and repeat their answer to check you’ve understood the point they are making.

- As the meeting gets closer, make sure copies of your child’s views, whatever the format, are circulated to everyone attending the meeting, along with your advice and those of others.
- Find out if your child wants to attend all or part of the meeting, or if they would like another person to present their views, and who they’d want that to be. Would they like to invite a friend or an advocate?

Setting ground rules for the meeting

‘One of the support staff said, “Chris, how can you say that?” and he just clammed up and didn’t say any more.’

Meetings are more successful when there are clear arrangements in place that take account of a young person’s particular needs. Check with the school what the ground rules are and be prepared to make your own suggestions and ask for changes if you think certain things won’t work.

Ground rules before the meeting could include:

- A meeting place that’s accessible and familiar.
- A meeting time when the young person’s best able to contribute.
- Clarity over whether your child will be there for some or all of the meeting and, if they’re only there for a part of it, which part it is.
- The opportunity for your child to choose where they sit.
- If your child usually needs someone to interpret for them, clarify with them and the school who that will be before the meeting. It’s confusing if everyone tries to help.
- Agreeing what will happen if the young person wants to leave the meeting or take a break.
- Getting the meeting recorded or someone nominated to take notes on your child’s behalf if that’s what they want.
Checking if there’s anyone the young person wants to be present for only part of the meeting.

Ground rules at the meeting could include:

- Introducing your child to anyone they don’t know at the meeting and explaining why they’re there.
- A reminder that it’s your child’s meeting and what needs to be discussed should be central to their future.
- Agreeing not to challenge what he or she says, interrupt them, or finish their sentences for them.
- Checking your child feels their questions have been answered and, if not, giving them the opportunity to ask again.
- Recapping what each person has agreed to do after the meeting.
- Checking your child understands what has been agreed and what will happen next.

‘The Casework Officer said, “I’m here to write down what everyone thinks should happen next.’

After the meeting

- Check out how your child feels. Maybe he or she wants to go over what happened. Perhaps there is something they would like done differently next time.
- Make sure your child gets a copy of what was agreed in a format that is accessible to them.
- Suggest your child keeps their notes, along with the minutes and recommendations, somewhere safe in case they want to look at them again.
- If your child has clear views about important matters, make sure they’re reflected in amendments to their EHC Plan.
- If it hasn’t been possible to act on your child’s wishes, find out who will explain the reasons for the decision.
- Encourage your child to be involved in putting recommendations into practice.
What if things go wrong?

However much groundwork you have both done, however well-reasoned the young person’s arguments, and however well supported your child has been, it’s possible your child might not get what they want.

However, decisions with long term implications can and will be reviewed, and many decisions can be challenged. If you’re unhappy with the decisions that have been made, this might be the time to get some professional advice. For more on this turn to page 23. There are also links to national organisations who may be able to offer information and support on pages 24 to 26.
Further education (FE) is learning mostly for young people between the ages of 16 and 19. It includes school sixth forms, sixth form colleges and further education (FE) colleges. Some FE is open to older people who wish to catch up on their education, or do vocational and access courses.

Higher education is provided by universities and similar institutions that offer degrees and Higher National Diplomas (HNDs).

Further education is often the first option for our young people when they leave school. Initially, the range of choices can feel overwhelming, but many of us found we quickly narrowed it down to just a few possibilities.

This chapter will examine those options in more detail, tell you about the kinds of additional support available in further and higher education and give you advice on how you and your child can make the best choices for their future.

It is important to remember that when your child reaches 16 years of age, their views, wishes and aspirations are recognised in law as the priority.

If they need help to think through their options, they can get advice from West Sussex SENDIAS. Its Young People Advisers can support young people up to the age of 25. For more details, call: 03302 228 555 or email: send.ias@westsussex.gov.uk (parent carers) or cyp.sendias@westsussex.gov.uk (children and young people).

The end of Year 11 – what next?

All young people are entitled to free full-time education until they are 19. The changes to
education law, called ‘Raising the Participation Age’, means that all children and young people have to stay in some form of education or training until their 18th birthday. There are some exceptions, such as those joining the armed forces, young people who become parents and those who are full-time carers for family members. However, this does not mean that they have to stay on at school when they finish Year 11. Options open to your young person include:

- Staying on at school, if the school has a sixth form.
- Going to a sixth form college.
- Going to a further education (FE) college.
- Going to a special school sixth form such as Manor Green College or Oak Grove College, if they have complex needs.
- Going to an independent special school or college, which could be residential.
- Doing work-based training such as an apprenticeship.
- Combining part-time accredited education and training with work or volunteering that lasts for more than 20 hours per week.

- Some young people may want to leave education behind and look for a job, but remember they’ll now have to combine this with training until they’re 18 years old.

From Year 9 onwards, your child’s Annual Review should focus on outcomes for preparing for adulthood, which we outlined briefly on page 12. You can find out more about outcomes by going to: www.preparingforadulthood.org.uk.

By the time your child reaches the end of Year 11, their chosen path should be clearly mapped out in their EHC Plan. All young people should be made an offer of learning by the end of September after they complete Year 11.

‘I didn’t know Beth had a right to full-time education until she’s 19. No one explained it to me.’

Getting the right paperwork in place

Under the old system, a child’s Statement of SEN would cease when they left school. Under the new system, EHC Plans can
continue if needed until at least 19 years of age, and in some cases up to the age of 25.

If your young person doesn’t have an EHC Plan, but feels they need more support than their school or college can offer they will be able to request an EHC Needs Assessment, with a view to getting an EHC Plan. Considering an EHC Plan is a good idea, especially if you feel your young person will continue to need support until they are 25 years old. You can find out more about EHC Needs Assessments on West Sussex’s Local Offer, see page 4 for details. You can also get advice from West Sussex SENDIAS, see page 18 for details.

If you feel you need further advice on SEND law and education, you can refer to IPSEA’s section for young people aged 16 to 25 years: www.ipsea.org.uk/pages/category/young-people-aged-16-25. As well as guiding you through the EHC process, it also has model letters, which you can download and adapt as part of your application.

Further Education (16-19)

Thinking about post-16 options

Your young person’s Year 9 annual review kick-starts the decision-making process with the first steps in transition planning. The school should provide information on post-16 options at this point, and as your child moves through Year 10 and 11.

There are many different courses available, so it is important to choose one that is the right level for your child. Ask your child’s teachers for their input. College websites can also be helpful.

‘I think what I found really hard was there are loads of options out there, but you have to do all the work. You know, you’ve got to find out what they are and then try and get your head around them all.’

16 to 19 Study Programmes

Study programmes are publicly funded programmes of learning for 16 to 19 year olds (or 16 to 25 year olds where the student has an EHC Plan). The programmes
Further and higher education

are based on a young person’s prior attainment and are designed to help students meet their educational and career goals.

For example, if a young person is academically able, they may study GSCEs or A levels. Other students may prefer to take a different route and study for an apprenticeship or gain other vocational qualifications such as a BTEc or HND.

Because providers have flexibility in the design, delivery and content of a study programme, it means that they can create highly personalised programmes for young people with a learning difficulty and/or disability.

Having said this, they still need to meet the Department for Education’s principles, which state that a study programme must:

- Provide progression to a level higher than that of the student’s prior attainment, although for students with a learning difficulty and/or disability this progression may be a broadening, generalising or consolidation of skills.
- Include qualification(s) that are of sufficient size and rigour to stretch the student and are clearly linked to suitable progression opportunities in training, employment or higher levels of education. However, students with a learning difficulty and/or disability can be exempted from this principle altogether if their needs are better met and progression better supported through structured non-qualification based activity.
- Require students who do not have GCSE grade 4 (what was grade C) or above in Maths and English to continue studying these subjects as part of their study programme. Students with a learning difficulty and/or disability need not have their English and Maths learning accredited but do need to have skills in these two areas included in their programme, as relevant to their individual needs and planned progression.
• Allow for meaningful work-experience related to the vocational area of the study programme, which develops employability skills and/or creates potential employment options. For a small number of students with learning difficulties or disabilities where employment is not their aim, even in the longer term, this principle can be disapplied, but study programmes should cover more creative employment opportunities for this group of students.

• Include other activities unrelated to qualifications that develop skills, attitudes and confidence to support the student’s progression.

Course levels and qualifications

This is a brief overview, but you can find out more about course levels and qualifications at the government’s website: www.gov.uk/what-different-qualification-levels-mean.

Entry level awards and certificates from the Open College Network and the Award Scheme Development and Accreditation Network (ASDAN) are courses that focus on independence skills. They are available in a range of subjects that focus on independence skills and are designed for students who want to build their knowledge but may not feel ready to study at GCSE level. Students can progress from Entry level 1 through to Entry level 3 if they wish, with each level having three sub-levels. Entry level 3 can help prepare students to access further courses such as GCSEs, NVQs and BTECs.

GCSEs and A levels cover specific subjects like Maths, English, History or Science. These are sometimes referred to as ‘academic’ qualifications.

NQVs and BTECs are sometimes called known as ‘vocational’ (work) qualifications that teach job skills that are defined by employers. They focus on a particular work area such as engineering, floristry or childcare, for example.
Further and higher education

NVQs (National Vocational Qualifications) can be studied by people in employment, or by school and college students who are on a work placement or working part-time. NVQs don’t have to be completed in a set length of time. There are five levels – from Level 1, which covers basic work activities, to Level 5, which is designed for senior managers.

The BTEC is a vocational qualification, often studied by 16 to 19 year olds. The Foundation/Introductory Certificate is equivalent to NVQ Level 1, the BTEC First Diploma is equal to NVQ Level 2 and the BTEC National Diploma is equivalent to NVQ Level 3, or three A levels.

Apprenticeships lead to work-based qualifications. They’re open over 16s who are not in full-time education. Young people doing apprenticeships have a contract of employment, usually for at least 30 hours a week and they work towards a vocational qualification.

Supported internships are another option open to young people aged 16 to 24 who have an EHC Plan. The internship is a structured study programme based primarily with an employer and aims to help young people achieve paid employment through learning in the workplace. Supported internships are unpaid, and last for a minimum of six months. Alongside interning at the organisation, young people complete a personalised study programme, which includes the chance to study for relevant qualifications, if appropriate, as well as continuing with English and Maths.

If your young person is thinking of following vocational or work-related learning at school instead of a traditional GCSE programme, make sure the units and certificates they’ve achieved at school are taken into account for the post-16 course they choose. These students could go on to Entry Level Programme Life Skills or Entry Level Vocational Courses at FE colleges.
If a young person over 18 has missed out parts of their education because of periods of ill health for example and doesn’t have traditional qualifications, they could do an **Access Course** to get into higher education. Access courses usually last for a year.

**Tips to help you**

- Find out what level your young person is working at before choosing a course, preferably in writing. Ask the school, or your child’s Educational Psychologist, if they have had a recent assessment.
- Find out the level of the courses on offer and ask if appropriate support will be available for your child.
- Young people who do not achieve English and Maths GCSEs at grade 4 (what was a C) or above by the time they are 16 years old are required to continue to study both subjects after the age of 16 alongside their other course(s).

**Choosing a setting**

**Sixth forms**

‘Sixth form’ is effectively Years 12 and 13 (and Year 14, if required). There are two types of sixth form: those that are attached to a secondary school and sixth form colleges.

School sixth forms and sixth form colleges cater for 16 to 19 year olds doing full-time courses. Young people with special needs attending sixth forms will be expected to join mainstream courses, but there’s learning support available to help them do this. Some colleges also have specialist programmes, so it is worth checking. If your child has physical disabilities or sensory impairments, check the access is suitable for them.

‘It’s more of an open environment in sixth form college. You’re left to your own devices more.’ (Lucy, 17)

If your child wants to continue their education in a school’s sixth form, you’ll need to discuss this
with the school in advance, but if the courses they want to do are on offer, the transfer should be simple. If they want to move to a sixth form at another school, contact the new school early on, as the school will have its own application procedure in Year 11. Sixth form colleges also have an application process. Your school can tell you about this.

**Schools with sixth forms in West Sussex**

- Angmering School, Littlehampton
- Bishop Luffa School, Chichester
- Chichester High School, Chichester
- Felpham Community College, Bognor Regis
- Hazlewick School, Crawley
- Holy Trinity School, Crawley
- Ifield Community College, Crawley
- Imberhorne School, East Grinstead
- Littlehampton Academy, Littlehampton
- Midhurst Rother College, Midhurst
- Oriel High School, Crawley
- The Regis School, Bognor Regis
- Sackville School, East Grinstead
- Shoreham Academy, Shoreham
- Sir Robert Woodard Academy, Sompting
- Steyning Grammar School, Steyning
- St Paul’s Catholic College, Burgess Hill
- St Philip Howard Catholic School, Barnham
- St Wilfrid’s School, Crawley
- Thomas Bennett Community College, Crawley
- The Weald School, Billingshurst.

**Tips for sixth form**

- Check the deadline for applying for sixth forms – your child will get priority if you apply by the right date.
- Sixth forms offer a full range of academic and vocational courses: including ‘A’ levels; BTEC at intermediate and advanced levels; RSA courses; Open College Network options; and the opportunity to take (or re-sit) GCSEs.
Further Education (FE) colleges

Like sixth forms, Further Education (FE) colleges have a wide range of academic and vocational courses and there is a full application process when your child is in Year 11. FE colleges also offer some higher education courses, too. They tend to have a broader range of vocational courses than sixth forms; these courses equip students for particular types of work including engineering, childcare, catering, hairdressing, IT or game development.

They also offer specific courses for students with special needs. These courses can run alongside mainstream classes for young people who have additional needs, or they can provide a stepping stone to more mainstream opportunities. It’s worth bearing in mind that ‘full-time’ courses at FE colleges usually mean around 16 hours a week, so you will need consider how your young person will fill the rest of their time.

FE colleges in West Sussex

- Crawley College, Crawley
- Chichester College, including Brinsbury Campus in Pulborough
- College of Richard Collyer, Horsham
- Northbrook Metropolitan College, near Worthing
- Worthing College, Worthing

Students can apply to go to any FE college. There will be extra travel costs if they opt for a college further from home, but it may be worth considering if the course is right.

Specialist sixth form education

For some young people with more complex educational needs, especially those with profound and multiple learning difficulties (PMLD) or severe learning difficulties (SLD) including autistic spectrum conditions, moving to a mainstream FE college might not be appropriate.

You and your young person may want to consider one of the specialist schools with sixth form provision within West Sussex:
There are also a number of independent specialist schools that educate children to 19 years. See the Further and higher education directory, page 260, for more information.

**Independent FE colleges**

If a young person’s needs can’t be met at a local college or sixth form, a specialist college may be an option. However, funding needs to be agreed with the local authority, the Education and Skills Funding Agency and, in the case of a residential placement, social care.

There’s a range of residential and independent FE colleges across the country and they specialise in post-16 education for young people with special educational needs. There can be waiting lists of up to three years for places, so it’s best to apply early.

Getting a place at an independent FE college isn’t straightforward. Fees are high and you need to prove that the young person’s needs can’t be met in the mainstream FE sector by collecting evidence to show that their needs, as described in their EHC Plan, can’t be met in local state provision. You will also need to show that local colleges have been consulted before a specialist college can be considered.

The views of the young person are also central to the application. It’s beneficial to include their views in the evidence you submit and you must show that they want to go to the college.

Getting funding for an independent specialist college is more complicated if you’re applying for a residential place.
Funding guidance is updated every year.

If the application is successful, funding will usually pay fees for up to three years (depending on the young person’s progress) and could require joint funding with social care and/or health services.

After 19, the Education and Skills Funding Agency will approach local health and adult social care services to share the cost of the ‘accommodation’ or ‘care’ component of the placement.

If funding is turned down, the local authority will advise on next steps and you can ask for the decision to be reviewed.

Other options

Asphaleia Training runs provision across West Sussex for young people aged 14 to 25 who may find mainstream education a struggle. They provide additional support to enable young people to make a good transition into further education or the workplace. For more information, go to www.asphaleia.co.uk.

Getting the information you need to choose

Prospectuses

Sixth forms and colleges have prospectuses that provide information about courses and facilities. You can ask for a copy of a prospectus by calling their Admissions Office. Many colleges also have them available to look at on their websites. If you don’t have internet access at home, you can access them at one of West Sussex’s FindItOut Centres:

- Adur: Lancing Youth Centre, Penhill Road, BN15 8HA
- Bognor: Church Path, Glamis Street, PO21 1DB
- Chichester: New Park Road, PO19 7XY
- Crawley: Centenary House, Woodfield Road, RH10 8GP
- Horsham: Youth Hub, Hurst Road RH12 2DN
- Littlehampton: 82 Wick Street, BN17 7JS
- Mid Sussex: 60 Park Road, Burgess Hill, RH15 8ET
- Worthing: 24 Marine Place, BN11 3DN
**Inspection reports**

Sixth forms and colleges are inspected by Ofsted. You can read the reports on the Ofsted website at www.ofsted.gov.uk. They can be quite wordy, but they give useful information on strengths and weaknesses, as well as indicating how establishments support students and measure quality. If your young person needs help making sense of Ofsted reports, contact West Sussex SENDIAS. It has Young People Advisers, who can support them with this, see page 18 for contact details.

**School visits**

Special schools and mainstream schools usually invite local colleges to visit and explain what they offer. Some pupils will also have done a ‘school link’ programme, where they may go to visit local colleges. If your young person wants to access a link course from Year 10, the school would need to arrange this directly with the college.

**Taster days**

Local sixth forms and colleges offer taster days, open days and open evenings each year. Check their websites for details.

**Other information**

The National Careers Service website has information and advice about education, training and work. Visit https://nationalcareersservice.direct.gov.uk. Or you can speak to a qualified adviser by contacting their helpline, which is available from 8 a.m. to 10 p.m., seven days a week on: 0800 100 900, or for text messages: 07766 413219. You can also speak to an advisor via their webchat service.

**Independent FE Colleges**

The NATSPEC website: www.natspec.org.uk is packed with information about specialist further education and includes a search function so you can look for colleges, as well as useful information about applying for courses.
Questions to ask to help you consider options:

- What are my child’s needs, what do they like doing?
- What courses are available and will they meet my child’s needs?
- Will my child need to study Maths and English in addition to the main course?
- What are the advantages and disadvantages of staying on at a school sixth form or opting for a sixth form college?
- What do local further education colleges offer?
- What are apprenticeships and traineeships and how do they work?
- How many hours a week is the course we are looking at?
- What will my child’s choice offer them?
- What course (or job) could they do after this?
- What support is available to help with the transition from school to the new setting?
- What additional support arrangements are provided?
- When would my child get their detailed support plan and when could they meet support staff?
- When should we apply for the course?
- What reasonable adjustments are needed to help my child with the application process, including the interview?
- Will my child need transport to and from the college and who will arrange it?
- Will my child be eligible for financial help to go to college and how can I apply for it?
- If local choices aren’t appropriate and my child wants to consider an independent residential college, who will pay the fees and how do I find out more?
- What happens after they finish the course?

Tips to help you

- Discuss education or apprenticeship and traineeship options with your child’s careers adviser.
- Find out what level your child is working at so you’re sure you are asking about a place on a course pitched at the right level.
- At sixth form, or sixth form college, students may not be
timetabled to attend lessons for a full day five days a week and class sizes vary. Check what support is available when lessons aren’t running.

- Also bear in mind that in a further education college ‘full-time’ education is usually around 16 hours per week. If your child is not able to study or look after themselves independently in the free hours how will you manage?
- Have a look at the colleges and ask about the extra and specialist support they can provide – it can vary between establishments.
- Often, prospectuses don’t mention provision for students with emotional or behavioural difficulties. If it is relevant to your young person, ask whether and how the colleges cater for this type of need.
- If you think what is offered locally is unsuitable, consider looking at colleges further afield.
- Identify who can help at each college and get their contact details.
- Don’t assume your young person’s school reports and EHC Plan will automatically be forwarded to a college. Make copies yourself and send paperwork directly to the Learning Support Coordinator or Inclusion Manager to ensure they receive them prior to your visit.
- Take more copies of your child’s paperwork with you when you visit, along with other relevant information to support your discussion with the Learning Support Coordinator or Inclusion Manager at the sixth form or FE college.
- Ask what previous students went on to do next.
- Arrange to look around the college when the students are in lessons.

‘One of the reasons I picked [the college] is that I don’t have to go up any stairs.’ (Andrea, 17)

**Applying to sixth forms and colleges**

Your child’s school may manage the application process if you’re applying to a college in West Sussex. Check with them.
If the school isn’t managing the process, make sure you get a prospectus for the institution you’re interested in. It usually has an application form at the back that you fill in and send off.

If your child hasn’t heard back from the sixth form or college within a month of sending the application form, offering an interview date, follow this up with the college admissions department.

**Interviews and offers**

Some sixth forms or colleges offer an initial interview that includes guidance for choosing the appropriate course, especially if the student is unsure or has unrealistic expectations before the course interview.

At the interview, the college fills in a report that is signed by the student and the interviewer. The report recommends a place on a particular course and the young person may be verbally offered a definite or provisional place at that point (depending on their exam results). A registration fee may be charged.

**Preparing for the interview**

Many parents worry about whether it is acceptable for them to go with their young person to the interview. Colleges often expect young people to discuss the details and arrangements directly with them. You could ask your child and be guided by what they want – if they feel they want you there to support them, that is fine.

Contact the Admissions department in advance to discuss the reasonable adjustments they may need to make for your child’s interview. There may be a group interview, a written task or another activity that is unsuited to your child, so you may need to discuss how the process can be made accessible to them.

‘We hadn’t prepared Beth for this because we had got used to it being second nature to interpret for her, or to think on her behalf. Suddenly this person was talking to her and she was just blank. We knew she was nervous and although she’d written out a list of questions to ask, it was just as well we went because he didn’t ask her if she had any questions so she just didn’t ask any.’
Questions to ask (before or at the interview)

- Do tutors have experience or training in the young person’s special need?
- Will there be support for your child in class and at what level?
- Will learning support be in place from day one and how long will it be offered for?
- Will the same support staff be with the young person for the whole course?
- What size are the classes?
- What does the course involve, for example are there theory classes, essays or group discussions?
- What’s the timetable like for each day?
- How many hours of independent study is expected each week? Is there any support available for this, such as a teaching assistant available to all students working in the library?
- What happens between classes? Is there any supervision?
- Where do students take their breaks?
- How are work placements arranged?
- Is transport to college or to work placements arranged? If it is, how and when do we need to apply?
- Is there support if the young person is struggling emotionally?
- Will speech and language therapy support be available?
- What days of the week and times will the programme run? (full-time courses don’t always run every day).
- Will the course definitely run even if only a few enrol?
- What other options are available if the course does not run?

After the interview

A copy of the report that was filled in at the interview will be sent to your young person formally offering a place on the course. An offer of a place may be made subject to getting certain GCSE results, but unconditional offers can be made for Foundation Level courses. Your young person will be asked to
complete an acceptance form and return it within two weeks.

The colleges arrange introductory days for students to meet tutors and other students. It’s a good idea to attend.

Support in further education

It’s helpful to know about the extra assistance offered to students when thinking about college options. Sixth forms and colleges cater for young people with special needs, but the way they do it varies.

Colleges and sixth forms need to take into account the Equality Act 2010, which says they must make ‘reasonable adjustments’ so disabled students are not treated less favourably and not discriminated against.

All colleges and sixth forms have a Single Equality Scheme, which you can usually find on their website. Ask them how they put this into practice for young people with special educational needs and disabilities.

‘The woman said they would get the tutors to only require him to do the minimum so that he didn’t fail and lose his confidence. They said if he needs extra learning support, they will try to provide it as he has missed seven years’ schooling due to his ME. They were really accommodating.’

What kind of additional support is available?

An EHC Plan will detail specific provision for your young person, but learning support is also available for young people who do not have an EHC Plan. They will be part of what is known as the ‘SEN Support’ group. Post-16 educational providers receive additional funding for these young people, so a wide range of support should be available from Learning Support departments. Types of support could include:

- Use of specialist software and equipment.
- Reasonable adjustments to teaching and learning and to physical access.
- Help with literacy or numeracy for individuals or in small groups.
• Sessions with mental health workers for learners with mental health difficulties.
• Support for learners with dyslexia or dyspraxia.
• Additional specialist teaching, for example for students with dyslexia, dyspraxia or discalculia.
• Provision for specialist services.

‘I said, “What level of support would you give, these are her difficulties,” and they said, “Oh, well you apply to the college and then we’ll tell you.” I said, “No, I want to know what sort of support you will give before I apply.” So I had to make another appointment to see a learning support person. We had a whole hour with them and it went quite well.’

It is a good idea to ask the education provider what sort of additional support might be available, as it may vary from one setting to another.

Most colleges have student support teams, who offer information and help on things like financial assistance, welfare services, accommodation, careers advice, health issues, study problems and personal difficulties. Colleges also have counselling services, which can help young people with personal matters.

What is not available?

It is unlikely services like educational psychology, speech and language therapy or physiotherapy will be made available at mainstream further education colleges, unless it has been included in an EHC Plan.

Specialist colleges may offer some or all of these services, but you should talk to someone from the college’s Learning Support Team to discuss your child’s needs and find out what support the college can offer them.

Tips to help you get the right support

• If your child’s staying on at a school sixth form talk to the SENDCo to see what support he or she will get.
• Don’t assume appropriate support will automatically be in place for the young
person. Make contact with the Learning Support Team at the college or sixth form and arrange a meeting to discuss how the needs of the young person can be met.

- Ask for confirmation of the level of learning support available to be sent to you in writing before the start of the course.
- Ask whether the college or sixth form has access to specialist support and if not, whether they will buy it in.

‘A tutor seems to have time to help him and he is very understanding. He said, “If he wants to put something on tape instead of writing I’ll let him do that.” It makes all the difference.’

We can’t stress enough the importance of doing your own research. Professionals will tell you about special courses offered at different colleges, but it’s unlikely they’ll pass judgement about the quality of them. Find out as much as you can about the courses your child is interested in and the support available to them, that way they are more likely to work out well.

‘I think the most useful thing was actually speaking to other parents who have already gone further down the line.’

What if things go wrong?

Even with all the preparation in the world, things can still go wrong. You will also have less contact with sixth form or college than you are used to having while your young person was at school, so it may be harder to spot issues.

If there are problems, talk to staff at the sixth form or college. They may be able to find a solution. Contact Learning Support as well as your child’s tutor.

If your son or daughter is struggling with their course, you may be able to find other courses they can transfer to quite quickly, but it’s not always so simple.

If the worst happens and your child leaves the college, they don’t lose their right to further education and training up to the age of 19 – if they have an EHC Plan, it can be free up to the age of 25, provided there is an educational objective or outcome.
Financial help with 16-19 education

All young people between 16 and 19 years have the right to a free full-time or part-time education, provided they satisfy national residence conditions, but additional financial help is available to some students.

Bursary fund

The 16 to 19 Bursary Fund provides financial support to help students overcome specific barriers so they can remain in education. There are two types of bursary.

The Vulnerable Student Bursary is available to defined vulnerable groups of students. These are: students who are in care; care-leavers; students who receive Income Support or Universal Credit because they are financially supporting themselves and someone who is dependent on them and living with them, such as a child or partner; and students who receive Universal Credit or Personal Independence Payment (PIP) in their own right. Education institutions must confirm that a young person meets one of the above criteria.

There are also limited discretionary bursaries, which can be used to support students facing genuine financial barriers like costs of transport, food or equipment. Sixth forms and colleges decide how much is paid and how often. Speak to Student Support services or a tutor to find out whether your child is eligible.

For more information, go to the Student Bursary Support Service at: www.gov.uk/guidance/student-bursary-support-service, or call their helpline: 0800 121 8989 (Minicom: 0800 917 6048) or email: C2L@studentbursarysupport.co.uk.

There are also two schemes offering residential support. The Residential Bursary Fund provides financial help for students attending an institution delivering specialist provision.

The Residential Support Scheme provides financial help to students who need to live away from home to study because the same (or similar) substantial Level 2
or Level 3 qualification is not available within daily travelling distance. For more information, go to: https://www.gov.uk/guidance/16-to-19-education-financial-support-for-students.

Other financial help

There may be other funds available to help with the cost of fees, equipment, childcare or travel. Students don’t have to be on benefits to get financial help – but funds are limited and do run out, so you should apply as early as possible.

You’ll need to fill in forms and provide evidence and financial details, so make sure you read through the institution’s guidelines on financial assistance before making an application.

What happens after 18/19?

In the last year of formal education, decisions about your child’s future learning or working life need to be made. The school or college programme includes links with local options for education, care or supported employment.

Young people don’t have an automatic right to stay on in education after they turn 19, but there are options and, in some cases, they may be able to stay in education until they’re 25. You’ll need to get individual advice, so ask your child’s school or college for help with this. For some young people this may be the point at which to consider a specialist further education college, see page 51 for more information.

‘After college I’ll be looking for a FE college like Plumpton. I would like him to stay in education until the last day, as long as possible.’

Young people who have done A levels or equivalent qualifications may want to move onto higher education.

Higher education

Going to university or a college that offers higher education (including FE colleges and
specialist institutions like art colleges) gives young people over the age of 18 the chance to acquire more academic qualifications.

Further education colleges often provide some higher education options – Higher National Diplomas (HNDs), higher level NVQs and degrees in partnership with universities, for example.

For part-time courses, you apply direct to the college, for full-time courses, the application process is through the University and College Admission Service (UCAS). Disabled Students’ Allowances (DSAs) can offer financial support – see page 66.

Just as it was for choosing post-16 options, research is really important in making the right choice for your young person. Don’t encourage your child to apply for a place until they’ve visited the university and considered the course carefully, as changing courses later can affect funding.

The range of degree and higher national diploma or equivalent courses on offer is detailed in university prospectuses. You can also find lots of useful information on the UCAS website at: www.ucas.com.

**Additional support in higher education (HE)**

Under the Equality Act 2010, it’s unlawful for universities and colleges to discriminate against disabled students. They have a legal requirement to make ‘reasonable adjustments’ so that disabled students are not put at a substantial disadvantage.

All higher education institutions should have a Disability Equality Scheme that sets out how they intend to improve disability equality across their organisation.

Telling the institution about your child’s disability in advance is advisable, particularly as EHC Plans lapse once young people begin university, so you must be proactive in talking to the setting to ensure that they understand your young person’s needs and can arrange for support to be put in place before their course starts.
For advice, you could call Disability Rights UK’s dedicated Disabled Students Helpline: 0330 995 0414 or email students@disabilityrightsuk.org. They also have online information and fact sheets to download at: www.disabilityrightsuk.org.

Most universities and colleges have disability coordinators or advisers. Contact the Disability Coordinator or Learning Support Coordinator for the university to discuss access and support arrangements and to set up a visit.

Visiting the university and speaking to the staff about your young person’s needs enables you to discuss any adaptations he or she may need and to talk to academic staff about specific course information.

It’s worth taking a list of questions to ask members of staff and students, as well as your young person’s EHC Plan, if they have one. What you want to ask will depend on your child’s disability or additional needs, but these are some examples:

- Are all the buildings physically accessible?
- Are there any particular facilities for disabled students?
- Are there any current students with a similar disability? If so, what type of support do they receive?
- Who will help organise support?
- Is there help to apply for additional funding if needed?
- Are methods of teaching and assessment appropriate?
- What would happen if there’s a problem after starting the course?
- Is there specialist university accommodation available, for example rooms on a quiet corridor, or with accessible, private bathrooms?

Student Unions and other help

Every university and most colleges have a Students’ Union (SU) that’s affiliated to the National Union of Students (NUS). They also have welfare services and can be a useful
source of information and support when you are considering applying to a university, or when you have been offered a place there. The Students’ Union office contact details should be included in the information you get on the institutions your child is interested in. Most universities will also have other support services for students, such as a student counselling service.

Tips

- Ask if there are any students at the place you are interested in who have similar needs to your young person. If so, try to speak to them if you can as this can help the young person assess whether the course and environment is right for them.
- It can be useful for you to talk to the student’s parents to get practical information and tips so you can help your young person to enjoy their new independence by ensuring they settle in well.

Funding for higher education

Going to university or college is a big investment, but students don’t need to pay any tuition fees up front. Instead, the fees are covered by a Tuition Fee Loan. The highest amount an English university can charge for annual tuition fees is currently £9,250.

Student Finance England also provides Maintenance Loans, which can help living costs like rent, food, books, transport and entertainment.

The easiest way to apply for student finance support is online at www.gov.uk/student-finance, or you can call their helpline: 0300 100 0607 (textphone: 0300 100 0622).

The website has a section for parents about higher education that should answer some of your questions. Your child shouldn’t wait until they have a confirmed place; they need to apply as soon as they accept an offer.

Make sure you do your financial homework before applying and
A guide to financial support for new full-time higher education students published by Student Finance England. It’s available from schools and colleges and online at www.practitioners.slc.co.uk. You can also find out more at: www.gov.uk/student-finance.

If your child has a disability or specific learning disability, it’s a good idea for them to contact universities and colleges to discuss their requirements before sending their application to UCAS.

Disabled Students’ Allowance (DSA)

Disabled Students’ Allowance (DSA) is a grant to help meet the extra costs students can face as a direct result of a disability, ongoing health condition, mental health condition or specific learning difficulty. It helps disabled people study on an equal basis with other students.

DSA is paid on top of the standard student finance package and it doesn’t have to be paid back. The amount your child may get depends on the type of extra help they need – not on your household income. DSA can be used for:

- Specialist equipment needed for study such as computer software, for example.
- Non-medical helpers, like a note-taker (scribe) or reader.
- Extra travel costs because of your child’s disability (see Chapter 11 for more about help with travel costs).
- Other costs, such as Braille papers for example.

It’s best to apply for DSA as early as possible, don’t wait until your child has a confirmed place at university as only limited support may be available from the university until the DSA has been organised. Visit www.gov.uk/disabled-students-allowances-dsas.

If your young person wants to be considered for DSA, complete a DSA1 form. Your young person will need to provide up to date evidence of their disability or condition (for example, a letter from a doctor or specialist or a ‘diagnostic assessment’ from a
psychologist or specialist teacher). If they last had an assessment when they were under 16, it will need updating. You’ll have to pay for any tests to establish whether your child qualifies for DSA. If you can’t afford to pay, you may be able to get financial help through the institution’s Access to Learning Fund.

If your child qualifies for DSA, Student Finance England will advise whether your child has to attend an assessment centre to work out what help they will need. The centre will write a report outlining what is needed and will send it to Student Finance England. The centre should also send a copy to your child.

For a guide to Disabled Students’ Allowances go to: www.gov.uk/disabled-students-allowances-dsas/further-information.

To find out how student income such as bursaries, loans and grants may affect existing benefits, speak to West Sussex County Council’s benefits advisor, Robert Hayes. For contact details, see page 107.
Friendships and having a social life are an important part of adulthood. Having friends who share similar interests, have fun with us, laugh at the same sort of things and share both the good and difficult times is immensely valuable. Young adulthood is the time when many people make friendships that will last a lifetime.

For teenagers with special needs, making friends and meeting up and going out with them can be trickier than it is for other teenagers. This may be because of mobility issues, not being able to travel independently or because he or she has communication difficulties.

‘He’ll go out now and again, but if he does go anywhere, we have to take him there and pick him up, because he can’t really get the bus to go on his own.’

Experiences at school or college can affect young people’s access to friends and leisure outside school. National research has found that many young disabled people experience isolation, loneliness and exclusion.

‘Ben’s doing really well at the day centre... He’s starting to make friends with his peers, but the fact is they’re so far away. It would be lovely to invite some of them back, if there weren’t issues with transport. That’s one of the downfalls about him going to a day centre out of his community.’

Many parent carers find that they have to do a lot to support their child’s social life and to help them meet new people or maintain friendships. Sometimes, they may find that they have to ‘share’ friends with their children because of the difficulties they face making their own friendships.
‘Friendship is the one area I get really sore about and every once in a while I have to take a step back. On the one hand, Oliver’s great company, he’s such a good laugh and we are good mates but I am his mum and there are times when I think, “Where are your own friends?” And what I find I have to do is double my friends up, and they’ve got busy lives. I’ve got to book them up twice. “If you come round at this time and Oliver can talk and then can we please go out another time when I can talk!” It’s tricky.’

Making friends

Many of us meet our friends through a common interest – work for example, a sport, an evening class, or through other friends. Parents whose children need more support with friendships might start by thinking about what their young person enjoys doing and then look for a club or an activity where they can meet other young people with similar interests.

It can be helpful to think about what other young people are doing, or to find places nearby that your child can go to on their own.

‘The pub’s just over the road, so he will go over there, which is really good.’

Local clubs and activities

There are lots of clubs and activities young people can try locally. Some of the ones listed below are open to children and young people aged from five upwards, while others are specifically tailored for teens and young people.

It’s a good idea to check whether a venue or activity listed here is a Compass Card partner as further discounts may be available – see the Compass Card entry for more information.

Many venues also run Assisted Access schemes, which entitle a disabled person’s carer free entry – ask when booking and take a copy of your young person’s DLA/PIP award with you to show at the till.

At the time of writing the following information is correct, however it is not exhaustive and we would recommend cross-checking individual providers with the Local Offer.
Listings marked (SB) are Short Breaks providers.

**Active Sussex** offers opportunities for young people with disabilities to participate in sporting activities across Sussex.

Tel: 01273 643869  
Email: info@activesussex.org  
www.activesussex.org

**Adur Special Needs Project** (Shoreham) runs various clubs for five to 15 year olds with special needs in Shoreham and the surrounding area.

Tel: 07788 239634, email: info@adurspecialneedsproject.org.uk  
www.adurspecialneedsproject.org.uk

**Air Arena Trampoline Park** (Chichester) has a variety of activities, including trampolines and climbing walls. Offers Helping Hands sessions for children and adults with learning difficulties or additional needs.

Tel: 01243 940530  
Email: info@airarena.co.uk  
www.airarena.co.uk/chichester.html

**Albion in the Community (AITC)** (SB) runs disability-specific as well as inclusive football sessions for young people with conditions such as cerebral palsy, autism and Down syndrome, sensory impairments and physical disabilities, at locations across West Sussex.  

Also see **Gully’s Days Out**.

Tel: 01273 668590  
Email: disability@albioninthecommunity.org.uk  
www.albioninthecommunity.org.uk/disability

**Allsorts Youth Project** offers support for all young people aged 5 to 25 who are LGBTU (lesbian, gay, bisexual, trans, unsure) or questioning their sexuality or gender. Runs youth clubs in Horsham and Chichester (one for those aged under 16 and one for 16+), and an emotional support phone line called **Talk it Out**.

Tel: 01273 721211  
Email: youth@allsortsyouth.org.uk  
www.allsortsyouth.org.uk/westsussex
**Angling4Education** (SB) runs inclusive fishing and forest schools sessions for young people aged four to 18 with SEND. Some sessions are also open to parents and carers.

Tel: 01273 968126 or 07795 410812
Email: angling4education@gmail.com
www.angling4education.com/sendprovision

**Apuldram Hub Club** is a social and activities club held in Chichester for adults with learning disabilities.

Tel: 01243 783370
Email: Hubclub@apuldram.org
www.apuldram.org/hub-club

**Arena Sports Centre** (Bognor Regis) runs a ten-week Access 4 All scheme for 16 to 25 year olds with SEND. Includes initial consultation and health screening. Free admission for carers exclusively supporting young people and adults with SEND.

Tel: 01243 870000, email: info@arenasportscentre.com
www.arenasportscentre.co.uk

**Ariel Othello’s** (Burgess Hill, Crawley, East Grinstead) Saturday daytime and weekday evening dance, drama, music, and singing for children and young people with SEND.

Tel: 01444 250407
Email: othellos@arielct.co.uk
www.arielproductions.co.uk/muse/special-needs.html

**Arun Sports Association for the Disabled** (Bognor Regis) runs sports for people with disabilities aged nine and above in Bognor, Chichester and Littlehampton.

Tel: 01243 583868
Email: enquiries@A-S-A-D.org.uk
www.a-s-a-d.org.uk

**Arun Sunshine Group** is a Littlehampton social club for adults with learning difficulties.

Tel: 01903 714930, email: derek@arunsunshine.org.uk
www.arunsunshine.org.uk

**Ashdown Centre** (Worthing) (SB) runs short breaks for young people with special needs. Ashdown Youth for those aged
12-18; Ashdown Extra for those aged 18-30 and Ashdown Siblings for over-fives who have brothers/sisters with SEND.

Tel: 01903 528600
or 01903 528607 (Ashdown Extra)
Email: ashdown@guildcare.org
www.guildcare.org/ashdown-centre

Aspens (SB) is the new brand for merged charities Autism Sussex and Pepenbury. It offers individualised support to children and adults with disabilities including autism and other complex needs, with a focus on transition to adulthood and independent living.

Tel: 01892 822 168
Email: enquiries@aspens.org.uk
childrenwsx@aspens.org.uk
familysupport@aspens.org.uk
www.aspens.org.uk

Asperger’s Syndrome Self Advocacy (ASSA) runs a social and activity club in Chichester and other meetings in Littlehampton.

Email: assagroupws@gmail.com
www.facebook.com/ASSAWestSussex

Autism Sussex, see Aspens

Barnardo’s Moving Forward Project (SB) Short breaks, providing sitter services, befriending and individual support. Emphasis on building confidence and independence through inclusive play, play/holiday schemes and enabling social inclusion and skills.

Tel: 01293 610692, email:
moving.forward@barnardos.org.uk
www.barnardos.org.uk/moving-forward-project-west-sussex-short-breaks/service-view.htm?id=261814047

Bluebird (Crawley), Blue Oasis (Horsham) and Blue Starfish (Worthing) run club nights and autism-friendly film screenings for young people and adults with learning disabilities or autism and their friends.

Tel: 01293 585350 (Crawley),
www.crawley.gov.uk/disabilitysport
Tel: 01403 215216 (Horsham),
www.facebook.com/HorshamBlueOasisClub
Tel: 01903 202030 (Worthing)  
www.worthingmencap.org/bluestarfish.php

**Boom Tribe** (Horsham) is an inclusive samba band that provides young people with the opportunity to socialise and perform at events.

Tel: 01403 215216, email: nick.jenkins@horsham.gov.uk

**Branching Out Club** (Chichester) (SB) is a monthly sports club for children and young people aged two to 18 years with disabilities. Held at Westgate Leisure Centre, activities include football, badminton, basketball, bouncy castle, soft play and table tennis. Site has hoist-assisted toilet.

Tel: 01243 785651  
www.everyoneactive.com/centre/westgate-leisure-centre

**The Bridge Leisure Centre** (Broadbridge Heath) (SB) runs discovery open days with a variety of activities for disabled children and young aged up to 18 years, their families and friends. Also has a sensory room.

Tel: 01403 211311  
Email: enquiries@thebridgeleisurecentre.org

**Brighton and Hove Albion** has recently introduced a wristband scheme for fans of all ages who have hidden disabilities such as autism. It discreetly identifies the user to all staff at the ground so that they know the supporter may need extra support in the stadium. For more information or to ask for a wristband to be sent to you contact:

Tel: 0344 3246282 (ask for supporter services), email: supporter.services@bhafc.co.uk.

**Brooklands Go Carts** (Worthing) offers speed-adjustable karts and assisted drives, where an instructor works the pedals.

Tel: 07867 762106  
www.brooklandsgokarts.co.uk

**Buddy’s Music Group** is held weekly at Buddy’s Café, Worthing. Sessions are run by Daniel Gilmore of Sussex Music Workshop. No need to book.
**Carousel** (Brighton) runs inclusive creative arts projects and groups for young people and adults with or without learning disabilities. Includes film, dance, music, and club nights. Runs the Blue Camel Club and Oska Bright Film Festival.

Tel: 01273 234734  
Email: enquiries@carousel.org.uk  
www.carousel.org.uk

**CEA card** is a scheme that allows a disabled person over eight years of age to take a carer free of charge to films at participating cinemas. There is a small charge for the card, which is valid for 12 months.

Tel: 01244 526016  
Email: info@ceacard.co.uk  
www.ceacard.co.uk

**Challengers Chichester Youthscheme** (SB) is a club for disabled teenagers aged 13 to 18 years that meets at Westgate Leisure Centre. Young people can take part in activities such as bowling, trampolining, or head into town to shop or have lunch.

Tel: 01903 202030 or 07771 880482  
www.worthingmencap.org/buddys-music-group.php

**Chanctonbury Community Play Scheme** (Worthing and Storrington) (SB) provides four weeks of volunteer-led respite care during the summer holidays for children aged four to 19 with special needs. More information can be found on their Facebook page.

Tel: 07455 131462  
Email: ccpsorganiser@gmail.com  
www.facebook.com/ccpsplayscheme

**Charlotte’s Tandems** loans tandems, tag-alongs and other equipment free of charge exclusively to people with disabilities or additional needs who are unable to ride a bike safely on their own.

www.charlottestandems.co.uk  
www.facebook.com/groups/CharlottesTandems
Chestnut Tree House (SB) provides care for children and young people aged 0 to 19 who have progressive, life-shortening conditions. It provides specialist short breaks and also runs a youth group and a buddy scheme.

Tel: 01903 871800
Email: cthadmin@stbh.org.uk
www.chestnut-tree-house.org.uk

Chichester Bowmen offers inclusive archery, with a one-off taster session for people to have a go, as well as longer archery courses.

Email: coaches@chichester-bowmen.co.uk
www.chichester-bowmen.co.uk

Chichester Fencing Club is held weekly at Chichester High School for Girls. The club also holds sessions at Arun Leisure Centre.

Tel: 01243 822753, email: info@chichester-fencing-club.org.uk
www.chichester-fencing-club.org.uk

Chichester Festival Theatre has a youth group, Chichester Festival Youth Theatre (CFYT), held specifically for young people and adults with disabilities, which meets on Friday evenings in Chichester and on Wednesday evenings in Horsham.

Tel: 01243 784437
Email: cfyt@cft.org.uk
www.cft.org.uk

Chichester Golf Club has a wheelchair-accessible adventure golf course.

Tel: 01243 533833
www.chichestergolf.com

Cineworld Cinemas hold autism-friendly screenings at Brighton, Chichester and Crawley in association with Dimensions.

Tel: 0300 303 9062
www.dimensions-uk.org

Cobnor Activities Centre Trust (Chichester) water activities such as sailability and a chairboat, plus off-water activities such as angling and archery. Also holds a week-long summer camp for people with disabilities, aged 14 to 45 years, which is wheelchair accessible (no hoist).

Tel: 01243 572791
Compass Card is a discount card for 0 to 25-year-olds with SEND in West Sussex. The card can be used at lots of leisure venues to get discounts or special offers. Please check website for eligibility criteria. A Compass app can be downloaded for iPhone or Android phones.

Tel: 0300 123 9186, email: compass@amazesussex.org.uk
www.compasscard.org.uk

Crawley BMX Track is an inclusive track run by Wheels for Wellbeing, that has specially adapted bikes and part-time instructors.

Tel: 01293 585350
Email: WheelsForWellbeing@crawley.gov.uk
www.crawley.gov.uk/bmx

Crawley Town Flyers is a football club for young people with special needs or disabilities aged 10 and over. Meets on Tuesday evenings at K2, Crawley.

Tel: 07877 327567 (Mo Hussain)

Crossroads Care South Central (SB) provides short breaks to children and young people aged 0 to 18 years. Workers meet with the family and together decide how the young person can be best supported for up to four hours a week to participate in leisure and social activities.

Tel: 01903 790270, email admin@crossroadscare-sc.org
www.crossroadscare-sc.org

Curiosity Hub runs regular inclusive tech events for children, young people and adults in Brighton.

Email: contact@thecuriosityhub.com
www.thecuriosityhub.com

Digital/Video Production course (Horsham) is inclusive and runs termly on Saturdays for young people aged 14 to 19 (age guide) and their siblings and friends.

Tel: 07747 565315 (Kim Roberts)
Email: kimberly.roberts@horsham.gov.uk
www.hdsd.org.uk/Inclusive-Activities/disabilities
**DJ’ing workshops**, for young people aged 12+ (age guide) with disabilities and their siblings/friends. Learn new mic techniques and put together a set to play at a **Blue Oasis Club Night** at these fully inclusive and accessible workshops.

Tel: 07747 565315 (Kim Roberts)  
Email: kimberly.roberts@horsham.gov.uk  
www.hdsd.org.uk/Inclusive-Activities/disabilities

**Dome Cinema** (Worthing) holds regular autism-friendly screenings, plus ‘disability-friendly’ screenings for teenagers and adults with other special needs.

Tel: 01903 823112  
Email: office@domeonline.co.uk  
www.domecinema.co.uk

**Downsman Bowls Club** and Crawley Blind and Disabled Bowlers is for people of all ages and abilities.

Email: info@downsmanbowls.co.uk  
https://downsman.secure-club.com

**Drusillas Zoo Park** is an accessible zoo located in Alfriston, near Eastbourne.

Tel: 01323 874100  
Email: info@drusillas.co.uk  
www.drusillas.co.uk

**Duke of Edinburgh Award** offers young people aged 14 to 25 the opportunity to help others, acquire new skills, experience adventure and make new friends, while at the same time working towards a nationally recognised award.

Email: dofe@westsussex.gov.uk  
www.dofe.org

**Duke of York’s Cinema** (Brighton) holds autism-friendly screenings.

Box Office: 0871 902 5728  
Email: enquiries@picturehouses.co.uk  
www.picturehouses.com/cinema/Duke_Of_Yorks

**Extratime** (Shoreham) (SB) is a holiday scheme for children and young people aged 5 to 18 with and without disabilities. Provides
a variety of activities, games, and trips out.

Tel: 01273 420580
www.extratimebrighton.org.uk/west-sussex-summer-2018-holiday-scheme

Ferring Country Centre (Worthing) provides training and work experience for people with learning disabilities. Garden centre, horse riding unit and café. Riding therapy for children and adults with a wide range of disabilities.

Tel: 01903 245078, email: office@ferringcountrycentre.org
www.ferringcountrycentre.org

Flamingoises Club (Crawley) is a swimming club for over 18s with physical or learning disabilities. Meets on Tuesday evenings at K2, Crawley.

Tel: 07880 178706
Email: kpford@outlook.com
www.crawley.gov.uk/disabilitysport

Flip Out (Chichester) offers trampolining and rebound therapy for all ages. Dedicated weekly SEND sessions. Portable hoist available.

Tel: 01243 256590
Email: chichester@flipout.co.uk
www.flipout.co.uk/locations/chichester

Footloose Dance Group is a dance and movement class in Crawley for children and young adults with learning disabilities. Classes run weekly in term time.

Tel: 01293 585350
Email: matt.laird@crawley.gov.uk
www.crawley.gov.uk/pw/Leisure_and_Culture/Sport__Activity_and_Wellbeing/Disability_Sport/

Forest Flyers Disability FC (Horsham) holds football coaching sessions for young people aged 10 and over with disabilities every Saturday at Forest School, Horsham.

Tel: 07747 565315, email: kimberly.roberts@horsham.gov.uk
Social life

**Fun and Breaks** has volunteers who support disabled children and young people up to the age of 18 with accessing social activities for two hours per week or four hours per fortnight. Requests for a referral should be made through the **Multi-Agency Safeguarding Hub** (MASH) – see Essential Directory for contact details.

**Gateway Clubs** social clubs for adults and older teens with disabilities.

Bognor: 07967 107783
Burgess Hill: 07592 609785
Crawley: 01293 516703
East Grinstead: 07592 609785
Horsham: 01273 492465
Lancing: 01903 764647

**Girlguiding** – the Senior Section is the Girlguiding group for young women aged 14 to 25. Fully inclusive and provides specialist funding and support to those with additional needs. Groups exist throughout the county, as detailed on the web pages below.

Tel: 0207 834 6242
www.girlguidingsussexcentral.btck.co.uk
www.girlguidingsussexwest.org.uk
www.girlguiding.org.uk
information-for-parents/support-for-additional-needs/

**Golden Lion Children’s Trust** organises days out for children and young people with special needs.

Tel: 01273 891963
Email: enquiries@glct.org.uk
www.glct.org.uk

**Grav Ity HQ** is a Friday night pan-disability social and activities club in Crawley for adults and young people from the age of 16. Search on Facebook for Grav Ity HQ.

Tel: 07877 327567
Email: gravity-hq@hotmail.com

**Gully’s Days Out** is a scheme run by Albion in the Community, which allows members to request tickets to a host of different attractions including: SEA LIFE Brighton, Butlin’s, Cineworld and Hollywood Bowl.

Tel: 01273 668590
Email: gullysdayout@albioninthecommunity.org.uk
www.albioninthecommunity.org.uk
Hack Horsham runs regular inclusive STEAM (Science, Technology, Engineering, Arts, Maths) workshops and events where people of any age can work on everything from Minecraft to coding and simple circuits to robot building.

www.facebook.com/hackhorsham

Head2Head Theatre (SB) is a provider of half-day activities for the whole family during the school holidays, which feature an interactive, multi-sensory ‘walkabout’ performance.

Tel: 01372 278021, email: anni@head2headtheatre.co.uk
www.head2headtheatre.co.uk/family-holiday-activities

Horsham Wheels for All provides a range of adapted bikes for people of all ages and abilities to enjoy cycling on the athletics track at The Bridge Leisure Centre (was Broadbridge Heath Leisure Centre). Meets on Friday evenings.

Tel: Paul Taylor on 07764 146339
Email: paul.taylor@horsham.gov.uk
http://cycling.org.uk/wheels-for-all

Impulse Leisure (SB) (Southwick) runs weekly rebound therapy for children and young people aged three to 18 with additional needs and disabilities, weekly inclusive family fitness classes (11+), and a monthly family roller disco (for 18 year olds and under and their families).

Tel: 01273 238111
Email: https://impulseleisure.co.uk/centres/southwick/short-breaks

Kangaroos (SB) runs the following clubs for teens and young adults with SEND: BreakAway Saturday and holiday club for ages 12 to 18 years; No Limits social programme for young people aged 18+; Youth Club for ages 18+ (alternate Tuesday evenings, Haywards Heath); Social Club for ages 25+ (alternate Tuesday evenings, Haywards Heath) and TeenScene Youth Club for ages 13 to 18 (Tuesday evenings, Burgess Hill).

Tel: 01444 459108
Email: lorna@kangaroos.org.uk
www.kangaroos.org.uk
KIDS (SB) offers Short Breaks to children and young people aged six to 18. Workers take small groups of young people on fun trips out.

Tel: 01329 312312, email: southern.shortbreaks@kids.org.uk www.kids.org.uk/chichester-short-breaks

Lodge Hill (Pulborough) (SB) accessible lodges and an activity centre that includes facilities for disabled people. See the Facebook page below for details of their regular activity days for young people aged up to 18 years with SEND.

Tel: 01798 831411 Email: admin@lodgehill.org.uk www.lodgehill.org.uk www.facebook.com/lodgehillcentre

Mid Sussex Marlins Swimming Club (Burgess Hill and Haywards Heath) runs swimming clubs for children and adults with disabilities: Starfish at Dolphin Leisure Centre, Haywards Heath, and Dolphins at the Triangle Leisure Centre, Burgess Hill.

General enquiries: info@midsussexmarlins.org Dolphins, email Pauline at: dolphins@midsussexmarlins.org Starfish, email Carolyn at: starfish@midsussexmarlins.org www.midsussexmarlins.org/disabilities

Mastersport Inclusive Sport provides sport and physical activities for young people and adults with disabilities. Opportunities are available in most sports, including angling, football, basketball, and boccia.

Tel: 01424 846951 / 07493 611 384 Email: roy.masters@mastersport.org.uk www.mastersport.org.uk

Moving Barriers Club (Crawley) runs sports and activities for children and young people aged six to 25 with disabilities. It meets every Friday at K2 Crawley. Call the Crawley Wellbeing team on the number below to find out more.

Tel: 01293 585350, email: sportsdevelopment@crawley.gov.uk www.crawley.gov.uk/disabilitysport
Music and Karaoke Club (Horsham) for children and young people with disabilities and siblings/friends. Lessons on guitar, drums and vocals in a wheelchair accessible professional recording studio.

Tel: 07747 565315, email: kimberly.roberts@horsham.gov.uk
www.hdsd.org.uk/Inclusive-Activities/disabilities

MXT Swimming School (Storrington and Steyning) has swimming teachers experienced in working with children with autism, muscular dystrophy, ADHD, dysphasia, dyspraxia and cerebral palsy.

Tel: 01903 202700 / 07903 731370
Email: mxtswim@gmail.com
www.mxtswimschool.com

National Autistic Society Horsham Club (SB) is for autistic children and young people aged between five and 18. It offers a variety of fun activities in a safe, autism-friendly environment.

Tel: 01483 521743 or 01483 521744
Email: SEResourcecentres@nas.org.uk
www.autism.org.uk/services/england/west%20sussex.aspx

Oak Grove College/Worthing Leisure Centre offers holiday and after-school clubs for young people with special needs. A range of activities are available including swimming, tennis, and trampolining.

Tel: 07762 013949, email: cmoyle@oakgrovecollege.org.uk
www.oakgrovecollege.org.uk/our-college-2/subjects/extended-college-activities/

Orchard Connect (Orchard House, Cuckfield) holds a youth club on Thursday evenings at The Park Centre, Burgess Hill. The West Sussex Disabled Young People’s Forum meets every four weeks on a Saturday at the Park Centre. Also runs a club every Monday during school holidays only. These groups are for young people aged 11 to 18 with SEND. Please email first if you are interested in attending, as booking is essential.

Tel: 01444 454226, email: martin.norris@westsussex.gov.uk
**Out of Hours** is a monthly social club for young adults with Asperger’s Syndrome. Meets at Buddy’s Café in Worthing.

Tel: 07503 177100  
www.worthingmencap.org/clubs.php

**Outreach 3way** runs several projects for young people with learning disabilities and autism, with a focus on promoting independence and building confidence and self-esteem. **Out There!** provides sports and leisure activities for people aged 16+. Daytime clubs run in Crawley, Burgess Hill, and Bognor Regis. Daytime and evening clubs run in Horsham, Worthing and Chichester. They also have a Day Centre in Ifield, Crawley, which runs groups and workshops and the **S.M.I.L.E** service, for people with profound learning disabilities to learn new skills.

Tel: 0300 303 9032  
Email: hello@outreach3way.org  
www.dimensions-uk.org/service/south/outreach-3-way

**PACSO** (Parents and Carers Support Organisation) (SB) runs a number of after-school clubs, youth clubs, weekend activities, and holiday playschemes for children and young people with special needs aged between five and 25 years.

Tel: 01243 533353  
Email: admin@pacso.org.uk  
www.pacso.org.uk

**Pavilions in the Park** (Horsham) (SB) runs swimming lessons for children and young people aged between five and 19 years.

Tel: 01403 219200  
www.placesforpeopleleisure.org/centres/the-pavilions-in-the-park

**People Come First** is a monthly Horsham group for adults with learning disabilities, run by adults with learning disabilities.

Tel: 07920 234605  
Email: Elizabeth.holmes@impact-initiatives.org.uk  
www.westsussexconnecttosupport.org
**The Point** is a resource unit for people aged 18 to 50 with physical or visual disabilities. It is run by Scope West Sussex in Chichester and offers a variety of activities and trips.

Tel: 01243 775330, email: info@scope-west-sussex.org.uk
www.scope-west-sussex.org.uk

**Rainbow Trust Children’s Charity** (SB) supports families who have a child or young person aged 0 to 18 with a life-threatening or life-shortening condition. Support can be provided at home or in the community and can include short breaks and family activity days.

Tel: 01372 220 111
Email: christina.cahill@rainbowtrust.org.uk
http://rainbowtrust.org.uk

**Ready and Able Sports Club** (Horsham) is an inclusive sports and social club for people aged 14+ that meets on Monday evenings (excluding bank holidays) at Bluecoat Sports Centre, Christ’s Hospital, Horsham. Activities include: football; table tennis; badminton; new age kurling; boccia; and swimming.

Tel: 01403 215637, email: paul.taylor@horsham.gov.uk
www.hdsd.org.uk/Inclusive-Activities/disabilities

**Reaching Higher Project** (SB) run by Horsham District Council holds term time after-school and weekend sports and arts activities for children and young people with additional needs and their friends and siblings. Activities include: archery; athletics; cricket; dance; rebound therapy and video production.

Tel: 07747 565315, email: kimberly.roberts@horsham.gov.uk
www.hdsd.org.uk/Inclusive-Activities/disabilities

**Regis Gymnastics** (Bognor Regis) is a gymnastics club that offers dedicated sessions of rebound therapy to children and adults with disabilities.

Tel: 07799 836341, email: regisgymnastics@gmail.com
www.regisgymnastics.com/Classes/disability.html
Riding for the Disabled Association (RDA) offers lessons at various centres around the county.

Tel: 01403 823212 (Annie Irving)
Email: annieirving@btconnect.com
www.rda-southeastregion.org.uk/how-we-can-help-you/find-a-group

Rhythmix Music Workshops are available to children and young people with disabilities, special needs or mental health conditions.

Tel: 08701 417484, email: info@rhythmixmusic.org.uk
www.rhythmixmusic.org.uk

SASBAH (Sussex Association for Spina Bifida and Hydrocephalus) runs social activities, a youth club, residential breaks and local community groups.

Tel: 01903 230782 / 01825 873045
Email: office@sasbah.org.uk
www.sasbah.org.uk

The Scout Association is an inclusive organisation where children and young people can experience the outdoors, interact with others, and gain confidence.

Explorers is for 14 to 18 year olds, while the Network section is for 18 to 25 year olds.

Tel: 01798 831110
Email: countyoffice@westsussexscouts.org.uk
http://westsussexscouts.org.uk

Short Breaks for Disabled Children commissions holiday clubs, after school clubs, buddy schemes, family fun days, and short breaks at home or in the community.

Tel: 0330 222 2562, email: SENDCommissioningteam@westsussex.gov.uk
www.facebook.com/groups/407136026068540/

SPACE for Girls is a club run by Aspens (formerly Autism Sussex) for young females aged 11 to 18 with social communication difficulties. Clubs run in East Grinstead and Worthing on Wednesday evenings. (Worthing, term-time only.)

Tel: 01243 214120, email: childrenwsx@aspens.org.uk
www.aspens.org.uk
Sport Without Boundaries is a charity that helps develop sporting opportunities for children and young people with disabilities. The sports involved range from boccia, new age kurling and tri-golf to swimming, athletics, cricket, tennis and football. Please contact the team on the details below to arrange your first visit.

Tel: 01903 890314, email: sandy@sportwithoutboundaries.co.uk
http://sportwithoutboundaries.co.uk

Springboard Project (SB) (Horsham and Crawley) provides a range of evening and holiday activities for young people aged 12 to 18 years. It also runs monthly social evenings for 18 to 25 year olds and a siblings club for children over 8 years.

Crawley – tel:01293 531963, email:sdmc@springboardproject.com
Horsham – tel: 01403 218888, email:sdmh@springboardproject.com
http://springboardproject.com

Sussex Cricket in the Community has disability hubs offering cricket and multi sports sessions.

Tel: 0844 264 0202. email: aroop.tanna@sussexcricket.co.uk
www.sussexcricket.co.uk/disability-cricket-o

Sunbeam Swimming Club (Horsham) is for disabled people of all ages that runs weekly on Fridays at the Pavilions in the Park. Prior to attending for the first time, please email Sarah Burling (coach).

Tel: 01403 253200, email: sunbeamenquiries@gmail.com
www.facebook.com/SunbeamSC

Sussex Otters Swimming Club (Chichester) is a swimming club for children and adults with disabilities. Poolside hoist available.

Tel: 01243 539181 (Hugh Fancourt) or 01243 582545 (Myrna Eccles)
Email: administrator@sussexotters.org.uk
www.sussexotters.org.uk

Steyning Leisure Centre (SB) provides swimming lessons for disabled people of all ages.

Tel: 01903 879666, email: enquires@steyningleisurecentre.org
www.placesforpeopleleisure.org/centres/steyning-leisure-centre
**Sussex Phab** (Lancing, Chichester, and Goring) runs clubs and outings to encourage people of all ages with and without disabilities to socialise together.

Tel: 020 8667 9443  
Email: info@phab.org.uk  
www.phab.org.uk/phab-clubs-our-phab-clubs

**Sussex Sailability** based at Sussex Yacht Club, Shoreham, caters for people with physical, learning and sensory disabilities. Facilities include a hoist to lift people from wheelchairs to boats.

Tel: 01798 812265, email: sussexsailability@gmail.com  
www.sussexsailability.org

**Sussex Sonics Wheelchair Basketball Club** (Brighton) is a wheelchair basketball club for people with disabilities.

Tel: 01273 307505 / 07767 754630

**Sussex Wasps** (Brighton) is a sports and social club for people with disabilities of all ages.

Tel: 01273 701235  
Email: archerphil@sky.com  
www.sussexwasps.weebly.com

**Tadpoles Swimming Club** (East Grinstead) is for people of all ages with various disabilities and diagnoses who would benefit from swimming and water therapy.

Tel: 01892 770232, email: thetadpoleseg@gmail.com  
http://tadpoles.info

**Time Aside** runs sensory art workshops at play schemes, parties, family fun days, and other events.

Tel: 07792 903236 (Sueloo)  
Email: sueloo@timeaside.com  
www.timeaside.com

**Tornados Wheelchair Basketball Club** (Littlehampton) meets every Friday. For anyone aged 12 and over.

Email: westcoasttornados@gmail.com  
www.tornadoswheelchairbasketball.co.uk
**Tuesday Group** is a Christian group for adults who have learning difficulties, social/and communication difficulties or other additional needs. Meets monthly in Chichester.

Tel: 01243 778500, email: info@GraceChurchTogether.org.uk https://gracechurchtogether.org.uk/graceworks/tuesday-group

**Westgate Leisure Centre** (Chichester) runs a club for people with disabilities and their families and carers (see Branching Out page 73). The centre has a large disabled changing area with fully working electric hoist and an electric changing bed.

Tel: 01243 785651

**Wheels for Wellbeing** (Crawley) makes cycling accessible to all. It has a range of inclusive cycles that will make cycling a fun, healthy option for people who might find regular bikes unsuitable. Wheels for Wellbeing sessions are run on a specialist, traffic-free, cycle track with access to adapted cycles for wheelchair users and people with disabilities. They offer coaching sessions, group rides and can be booked for group events.

Tel: 01293 585350
Email: WheelsForWellbeing@crawley.gov.uk www.crawley.gov.uk/ww

**Whizz-Kidz Club** (Crawley) enables wheelchair users aged 8 to 25 to make friends and have fun. Activities include music, dance, art, sports, beauty therapy, and cooking trips.

Tel: 07833 772949
Email: l.clarke@whizz-kidz.org.uk www.whizz-kidz.org.uk/get-our-help/young-people/ambassador-clubs

**Woodland Wonders Forest School** (Chichester and Horsham) offers a range of woodland experiences and bushcraft activities to the whole family. Provides sessions for young people with SEND and their families, plus six-week courses for adults with learning difficulties.
**Worthing Harriers** (Worthing Leisure Centre) has a wheelchair racing for all ages, as well as a Special Olympics athletics team for those aged 8+.

Email: cmoyle@oakgrovecollege.org.uk  
www.worthingharriers.com

**Worthing Leisure Centre** (SB) runs a variety of sports and activities for young people and adults with disabilities, including trampolining for children and young people aged up to 19 every Saturday afternoon; an inclusive football session for people aged 18 to 36 on Friday evenings. It also runs a holiday programme, Let’s Get Sporty & Creative for children aged 7 to 15, which must be booked in advance.

Tel: 01903 905050 (option 2)  
Email: enquiries@southdownsleisure.co.uk  
Football: w.poulter@btinternet.com

**Worthing Mencap** runs a day centre, sports club and other clubs and activities for people with learning disabilities and/or autism.

Tel: 01903 202030, email: buddys@worthingmencap.org  
www.worthingmencap.org

**Yip4Youth** (SB) (Crawley) is a daytime holiday youth club for young people aged 12 to 18 with any SEND. It runs on weekdays during the Easter and summer holidays. **Yip4Youth Buddies** (SB) (Crawley and Horsham) is a youth club promoting life skills and independence for young people aged 12 to 18 with moderate learning difficulties. Meets Tuesday and Thursday evenings during term time. Both clubs are run by YMCA East Surrey.

Tel: 01737 222859  
Email: Robert.Felgate@ymcaeastsurrey.org.uk  
www.ymcaeastsurrey.org.uk/yip4youth-crawley-horsham
Buddy schemes

A number of organisations now run buddy schemes, which enable disabled children and young people to access projects and services in their community via the help and support of a volunteer buddy. Like after-school clubs, these types of schemes also enable parents and carers to take a break.

Aspens (formerly Autism Sussex) – runs outreach schemes, day services and activities for young people and adults with SEND. See page 72 for contact details.

Gig Buddies – see Stay Up Late

Grace Eyre runs a friendship scheme for young people with learning disabilities. It offers people the chance to come together and plan what they would like to do with the support of a coordinator.

Tel: 07436 093120, email: GEFriendship@grace-eyre.org www.grace-eyre.org

Stay Up Late is a charity providing support to people with learning disabilities and/or autism aged 18+. Matches people with volunteer buddies to accompany them to gigs and other events via a scheme called Gig Buddies.

Tel: 01273 600438 Email: info@stayuplate.org www.stayuplate.org www.gigbuddies.org.uk

Help with the cost of activities

The Compass Card is available to children and young people who are registered on Compass West Sussex or Compass Brighton and Hove, the children and young people’s disability registers for West Sussex and Brighton and Hove respectively. All Compass data is processed and stored securely by Amaze under data protection legislation and families are asked to re-submit their child or young person’s information every two years to ensure that the Compass registers are up to date.
In return, families receive savings on leisure activities, including free swimming, cinema discounts, free gym memberships. Users can also download the free Compass Card app for iPhone and Android to check Compass Card offers on the move. Please see www.compasscard.org.uk for more information about who is eligible for registration and how to apply.

Horsham’s Leisure Access Card (LAC) allows residents to save up to 50 per cent on leisure activities and attractions across the Horsham District. To qualify you must live in Horsham District and receive a benefit such as Carer’s Allowance or Universal Credit. If you are aged over 16 and a full-time student, you are also eligible, so your young person may be able to apply for one themselves. The card can be used at leisure centres and visitor attractions in the district. For more information telephone 01403 215642, or email leisure@horsham.gov.uk.

Who else can offer support?

The role of parent and friend are very different and it is important to find ways of helping your young person to develop friendships outside the family. This might mean having a carer or assistant who is a bit closer in age to them, who can take them out and about or to activities. If your child has a social worker, you could talk to them about getting direct payments to pay for a personal assistant.

If you have had no involvement with social care so far, your child will need an assessment of their needs to see if they are eligible for support from social care. See the ‘Social care’ chapter from page 131 onwards for more information.

If you do get Direct Payments, Independent Lives can support you. It has a directory of personal assistants (PAs) looking for work, as well as a page for employers seeking PAs. They can also help with managing Direct Payments. Visit www.independentlives.org or find out more in the Social care chapter.
‘We use Direct Payments to pay for support for Rachel. Her PAs are her friends, because she has no one. She has no friends. She can’t sustain a friendship. That’s part of her difficulty. But I see these two carers as her friends.’

Not all young people find it easy to socialise. Some may prefer to socialise online – but you’ll need to check this is safe. A number of organisations such as have information and guides to help families with internet safety. For further information about internet safety go to page 101.
Part of growing up is about developing good self-esteem, a positive body image, and the confidence to be happy with who you are as a person, as well as developing a sense of responsibility for your own actions.

**Building self-esteem**

Building self-esteem so that your young person feels happy and confident is extremely important for all children, and especially so for those with SEND. You can help them in the following ways:

- Celebrate their successes, no matter how small. Make sure your young person knows how proud you are of everything they do.
- Make sure you compliment them every day – this could be something as simple as telling them they’ve made a good choice.
- Remind them of all the things they are good at and, if things do go wrong, reassure them that everyone makes mistakes occasionally.
- Feeling that their opinions are valuable and respected will help your young person to be able to speak up, which will help when they have meetings with professionals.
- Encourage your young person to make their own decisions. You can help them to do so (see page 32 for more on this), but remember to respect their choices if they are not what you were hoping they would decide on!
- Encourage your young person to be assertive with others. Teach them how to deal with people who ask them questions about their disability that they may not want to answer. For example, tell them that it is okay to change the subject if they do not feel comfortable.
• Remind your child of the fact that everyone is different and that this is OK. It can be really helpful to find positive role models for your child to relate to. Look out for news articles and photos that you can share with them.
• Encourage your child to keep clean, use deodorant, wash their hair regularly and so on.
• Like many teens, your young person may want to experiment with clothes, hairstyles and make up. Help them to try out different looks, even if it’s not something you would wear, and encourage them to find their own style.
• If your child is self-conscious about certain aspects of their appearance, don’t dismiss their concerns. Listen to them and support them by helping them to talk through their feelings. It’s important to tell them that everyone has things they do and don’t like about themselves. If you can get them to talk about their good points to focus on some positive aspects this can help them to feel more confident about their appearance.

Puberty and sex education

What does my child need to know?

Growing up is also about having relationships and becoming a confident adult who may have a range of close friendships and sexual partners.

Some parents may find talking to their children about puberty and sex slightly awkward. However, for all children and young people, regardless of whether or not they have a disability or special needs, being open and honest from an early age is important. Puberty and the swirl of confusing adolescent emotions that go with it is far easier to cope with if a young person knows what is happening to their body and what changes to expect.

It’s a good idea to start talking to your child about how their body works and grows from an early age and to gradually build on their knowledge as they get older. If they ask questions, be honest with them and factual, but
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don’t feel like you need to go into too much detail in one go, which can be overwhelming. Building a child’s knowledge slowly and at their own pace will be far less scary than having to sit down and have the ‘big talk’ about sex.

You may also find it helpful to contact the FPA (formerly the Family Planning Association), which produces a range of leaflets and a DVD to help parents overcome difficulties talking about puberty and sexual issues with their children. The site also has advice and easy-read resources for young people with learning disabilities. For more information go to: www.fpa.org.uk.

What words should you use?

Use words your child is familiar with and gradually introduce the correct medical names for the genitals and other body parts. Even if your child chooses to use their own words, it’s helpful if they can understand and use the correct medical terms in certain situations.

This is especially important if your child is going to be in hospital on their own. They may be embarrassed if they can’t explain a problem to a doctor or nurse because they don’t know the correct words. If your child needs personal or intimate care, consistency in the language used to describe the genitals and other areas of the body is also very important.

If your child relies on the help of support workers when going to the toilet, or if they are used to undressing regularly for doctors or therapists, the concept of parts of the body being ‘private’ may also need reinforcing.

Puberty

Young people with special needs go through puberty like any other child. Although puberty may be early for some and delayed for others, it is a biological and emotional process that has to happen. As far as possible, all children and young people need to be prepared for the changes that will happen to their body before they take place.
Every young person is different, but here are a few ideas that you might want to consider talking about:

- The name and function of the sex organs.
- What changes to expect at puberty.
- How society expects them to behave in public.
- Keeping safe from exploitation and abuse.
- Relationships and responsibility.
- Preventing unplanned pregnancy and sexually-transmitted infections (STIs).

Schools cover puberty, sex and relationships in science lessons and also as part of ‘PSHE’ (Personal, Social and Health Education), and you may want to talk to a teacher at school about your child’s sex education programme, especially if you feel they might be anxious or if you feel they might benefit from a chat at home beforehand.

Your child may also need some points to be reinforced at home afterwards. They may come home with worries relating to their medical condition or disability.

If possible, you need to be able to allay their fears. If you don’t have the answers, you could contact the support group for your child’s condition (see the local and national directories at the back of the book for further information).

**Periods**

Girls can begin to have periods from around the age of nine, although it’s also normal if periods do not start until a girl is in their teens.

Make sure that you have covered menstruation well before the first period, so that your daughter knows it is a normal process and nothing to be worried about.

Explain that her period will stop after a few days and that it will happen again. Once her periods have started, it’s a good idea to mark it in a diary or on an online app so that she knows roughly when it will happen again.

You should also give her information about pads and
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Tampons so she knows what they are for and how they are used. It is a good idea to buy some and take them out of the wrappings. Usually pads are quite easy for a girl to put in place herself, but sometimes she may need help because of the nature of her special needs or disability.

Emphasise the importance of personal hygiene and cleanliness during menstruation. Make sure that your daughter knows that periods are private and she should not talk about them with everyone, but that it is OK to talk to you, a teacher at school, a nurse or a friend if she wants to or has any questions.

**Personal care**

Children and young people who need intimate personal care may find it awkward or embarrassing as they get older and go through puberty. It’s important, therefore, to ensure that you or any carers who provide personal care are respectful and sensitive towards your young person. You can do this by:

- Giving your young person a say in their personal care plan.
- Making sure that the care plan is assessed and updated as and when your child’s needs change.
- Finding out if there are ways that your young person could manage their intimate care needs themselves, using aids or equipment.
- Making sure that the number of people who provide intimate care to your young person is kept to a minimum.
- Asking your young person before you provide intimate care and ensuring that they know why it is needed.
- Keeping things consistent – ensure that anyone who provides intimate care to your young person uses the same language for parts of the body and functions.

**Masturbation**

Exploring your body and getting to know what feels good is natural as you grow up, but for young people with disabilities, there may be issues with opportunities and privacy. As for any adolescent,
your young person’s right to privacy should be respected. Try to knock and wait before going in to a bedroom or bathroom and ensure that other carers, including support workers, do so too.

Some young people with learning disabilities may need extra support to understand that while masturbation is okay in private, there are times and places where it is not acceptable. As mentioned in ‘Useful resources’ on page 100, there are a number of leaflets and books available, including some easy to read books that will help you discuss things with your young person in a way that is appropriate for them.

**Sexual relationships**

In the past, it was commonly believed that young people with disabilities did not have sexual feelings or needs and that if their disabilities were complex that they did not have the capability to have sex. They do, and part of helping your young person on their journey to adulthood is to acknowledge this, so that you can give them the knowledge they need to form safe, loving relationships.

Many parents worry that teaching their young person about sex will encourage them to become sexually active at an earlier age. However, children who have received sound sex education are more likely to wait and become sexually active later than their peers.

Avoiding talking about sex will not make your child’s sexual development, feelings and desires go away, but it may leave him or her feeling confused and fearful, especially if they misunderstand what they’ve learned or hear wrong information from peers.

This is especially true today, with so many teenagers having ready access to the internet – it is far better that your child learns about sex in a safe, secure way by talking to you, than by someone at school showing them inappropriate images or videos.

It is great if your young person feels that they can talk about
their feelings and needs with you. Not only will this give them the support they need to deal with difficult adolescent feelings, it will also give them the security to discuss any anxieties they may have about anything that makes them feel uncomfortable.

As a parent, you will play a vital role in supporting your young person through adolescence so they can become confident, knowledgeable adults who can make good, informed choices. Being open and honest when you talk about sex is really important, as is ensuring that your young person has access to good sex education and health care.

**When and how to talk about sexual relationships**

- Talk to your child from an early age, certainly before puberty.
- Chatting casually and openly while you do other things will also help children to feel that sex is normal. You may find that a TV programme or a book triggers a conversation, for example.
- Answer questions and don’t be afraid to say, “I don’t know. Let’s look it up together.”
- Answer the question they’ve asked. If they want to know more, tell them, but don’t overcomplicate the issue and don’t sit them down for a ‘big talk’ as it can be overwhelming to try to absorb all the information at once.
- Talk to your child about mutual love and respect.
- Make sure they are aware of all the different types of relationships and the fact that same-sex relationships are as common for disabled people as non-disabled people.
- Share your own beliefs and attitudes but be prepared to listen to your child, too. They may have different views on things.

**Protecting your child from abuse**

There are a number of reasons why disabled children and young people can be more vulnerable to abuse. Their learning disabilities may mean that they have less understanding about private
parts of the body, particularly if they rely on intimate care or have frequent medical examinations where they need to undress. Or they may have communication difficulties, which affect their ability to speak out about abuse. So the need for sex education and an understanding of appropriate touch is essential.

Try to make sure that your child understands the difference between wanting to be touched and kissed and being made to do something that makes them feel scared or uncomfortable. Teach them that their body belongs to them and that it is not okay for someone to touch them if they do not want them to.

Be sure that your child knows that they can talk to you (or someone else they trust) about anything, no matter how awful or embarrassing it feels. If your child uses signs or symbols, be sure to introduce ones that allow them to communicate with you or others about their body and feelings.

However, it is important to keep these risks in perspective.

Give your child the confidence, knowledge and skills to protect themselves, without over-protecting them or stopping them from experiencing all the good things that life has to offer.

**Useful resources**

There are a number of good resources to help you explain changes during puberty to a child with learning disabilities. *Talking together about growing up: a workbook for parents of children with learning disabilities* by Lorna Scott and Lesley Kerr-Edwards is available from FPA. See their website www.fpa.org.uk.

*Let's Talk about Sex* by Robie Harris and Michael Emberley (Walker Books) covers all aspects of growing up.

Contact’s *Growing up, sex and relationships* booklet also goes into more detail about puberty, relationships and other issues around growing up. It also has a variety of useful contacts to other organisations that may be able to help you.
There are also a number of books written for children and young people with additional needs that explain many topics around this subject. Jessica Kingsley Publishers produce numerous titles relating to disabilities and special educational needs, including a series of easy to read picture books. They cover puberty, masturbation and sex, as well as a guide to using public toilets safely. They also publish *The Growing Up Guide for Boys* and *The Growing up Guide for Girls*, which are geared to young people on the autistic spectrum, as well as books written by young people with autistic spectrum conditions. For more go to: www.jkp.com.

Books Beyond Words produces a series of booklets illustrated in full colour and with few or no words for people with learning disabilities to help them to understand relationships and health issues. Go to: www.booksbeyondwords.co.uk.

Scope has a number of links to material for people with learning disabilities. Go to: www.scope.org.uk/Support/Families/Parents-and-Carers/Landing/Learning-disability/Sex.

BILD (British Institute of Learning Disabilities) has information and resources for parents and young people covering everything from friendships to relationships and sex. They also have easy read information. For more go to: www.bild.org.uk.

If your child is confused about their sexuality, you can get advice and support from the Switchboard Helpline on: 0300 330 0630 or go to: www.switchboard.lgbt.

You can also contact Young Stonewall at: www.youngstonewall.org.uk.

**Online safety**

Computers, tablets and smart phones are such a central part of every day life, that it is inevitable that our children will want to go online. It’s a constant source of worry to all parents – how do
we balance freedom to use the internet while still keeping our children safe from its darker side?

Fortunately, there are plenty of resources to guide us through the online maze to ensure that our children and young people can explore safely. For general advice about online safety, the following sites are useful:

Family Lives offers advice on keeping teens safe online, with resources on chat rooms, gaming and sexting: www.familylives.org.uk/advice/teenagers/online/online-safety.

Get Safe Online is a website with tips and explanations about everything from social media to banking: www.getsafeonline.org.

The NSPCC also has advice about keeping children safe online, with guides to setting up parental controls. Go to: www.nspcc.org.uk/preventing-abuse/keeping-children-safe/online-safety.

Thinkuknow has information about online safety and how to keep your child/young person safe and how to set up parental controls. Go to: www.thinkuknow.co.uk/parents.

For those of us whose young people have learning disabilities, there are a number of sites that offer advice and resources that are specifically tailored for our young people: for example, the Foundation for People with Learning Disabilities: www.learningdisabilities.org.uk/publications.

Mencap has created internet safety training for people with learning disabilities. To find out more about SafeSurfing, go to: www.mencap.org.uk/about-us/our-projects/safesurfing.
Most of us are used to claiming benefits to help meet some of the additional costs of caring for our disabled children.

As well as Disability Living Allowance (DLA), many of us may have claimed additional benefits like Carers Allowance and disabled child tax credits. We get used to having this money around; it becomes part of the family budget. Often, it pays everyday household bills, especially if parents can’t work or work part-time.

This chapter is an overview of the benefits you and your child might be getting now and what changes as your child reaches 16. We also look at other sources of help like Motability, Direct Payments and grants. If you need information on funding for students, you’ll find it in Chapter 3, ‘Further and higher education’.

This is a starting point for you to have discussions as a family about what might be appropriate for your own particular set of circumstances. We strongly recommend that you seek further professional advice to check that you are claiming all of the benefits that you are entitled to and to ensure that you make the right financial decisions for you and your young person.

You can get expert individual advice from West Sussex’s benefits advisor, Robert Hayes, see page 107. Further information and advice is also available from many national organisations, including:

- Cerebra: www.cerebra.org.uk/help-and-information/guides-for-parents/money-matters
- Contact: https://contact.org.uk/advice-and-support/benefits-financial-help
Changes to the benefit system

The benefit system is currently undergoing some big changes, with many familiar benefits being replaced by Universal Credit (UC). This is an integrated means-tested benefit for people in or out of work. It is replacing the following benefits, which are now called ‘legacy benefits’:

- Child Tax Credits
- Employment and Support Allowance (ESA)
- Housing Benefit
- Income Support
- Job Seeker’s Allowance (JSA)
- Working Tax Credits

Alongside these changes, Personal Independence Payment (PIP) has replaced Disability Living Allowance (DLA) for anyone aged over 16 with disabilities. Under 16s with disabilities continue to claim Disability Living Allowance (DLA).

At the time of writing, there is still some way to go until all benefits claimants have been moved on to Universal Credit. Although Universal Credit has been rolled out in West Sussex for most new claimants and also for anyone who notifies the Department of Work and Pensions (DWP) of a change in their circumstances, there are some exceptions.

Currently, families with three or more dependent children claiming legacy benefits cannot apply for Universal Credit, even if they report a change in their circumstances. Disabled adults in receipt of a payment called the ‘severe disability premium’ will also be exempt from claiming Universal Credit. Seek further advice if this applies to you.

The government plans to move all claimants on to Universal Credit some time between 2019 and 2023.
**Universal Credit allowances**

Universal Credit is made up of different elements. You can claim a standard element as a single or joint claimant and other elements if you are eligible. These include a child element for people with three children or fewer, work allowances, housing costs, childcare costs and an additional amount if your child or young person has a disability.

**What changes at 16?**

Generally, there is an expectation that parents are responsible for their child’s ‘keep’ up to the age of 20. So, as long as your child stays in full-time education at school or college or certain types of approved work-based training, under the current system you can continue to claim the following benefits for them:

- Child Benefit, as long as their parents’ individual income is not greater than £50,000 a year.
- Child Tax Credits (if you do not yet claim Universal Credit), or you can claim additional elements for a dependent child or young person as part of Universal Credit.
- Additional amounts paid for a child or young person through legacy benefits such as Income Support, Jobseeker’s Allowance, Housing Benefit.

**What you must do**

However, to ensure these payments continue, you must notify the relevant benefits offices that your child is continuing in education or approved work-based training after Year 11.

We have heard from parents in West Sussex who did not know this and found themselves in a tricky situation as their Child Tax Credits stopped. Because young people must stay in education or training until they are 18, they thought that their Child Tax Credits/additional UC allowances for a dependent child would continue automatically, but they don’t.

To ensure that you have continuity in your benefit payments, you must let your benefits office know...
that your young person is staying in full-time education and what course they will be studying, no later than 31st August. You must do this every summer until your child finishes their further education – usually when they are 19. The Child Benefit Office should send you a form to fill out to say that your child is staying in education or training. If you do not return it, your Child Benefit will also stop.

This is an example of things that can catch parent carers unawares, and it also highlights the need for good planning. At some point in the near future your benefit payments may reduce if your young person leaves home to live more independently. Start thinking about how you will manage without your child’s contribution.

‘Half our household income comes from money because of James’ special needs. He’s already decided he’s leaving home when he leaves college, so if I don’t start planning for my future, I might end up destitute!’

**When should a young person claim benefits as an adult?**

When a young person reaches 16, they have the right to manage their own money or ask someone else to do it for them. This means that young people have the option to claim benefits in their own right. This can be the key to your young person getting other sorts of help. They may be able to get benefits like Universal Credit, as well as other sources of financial help.

If your child can manage their own money, it makes sense for them to claim PIP for themselves at 16. Even if they do, they can still be considered a child for the purposes of other Universal Credit allowances and Child Benefit. For more PIP, see page 109.

However, if your child claims Universal Credit in their own right, you will lose any benefits you get for them as a dependent, even if they remain in full-time non-advanced education or approved training. So you will need to weigh up whether it
is best for your young person to claim in their own right or continue claiming benefits for them as part of your family.

The decision you make will depend on your circumstances. You will need to compare what you get now, claiming with your child as a dependent, against what they will get if they claim in their own right. If they do claim their own benefits, how much will you lose?

Reasonably well-off families who don’t qualify for the child element of Universal Credit (or Child Tax Credits under the old system) or receive just a small amount may find that their household is better off if their young person claims benefits in their own right.

Those on lower incomes who get more Universal Credit may be worse off if their young person claims benefits in their own right, as you could see a reduction in your allowances overall.

To get a clear picture of what is best for your family, it is sensible to get expert advice before you make any decisions. You can contact Robert Hayes, West Sussex County Council’s benefit advisor, at: robert.hayes@westsussex.gov.uk, giving your child’s name and age as well as your contact details and he will get in touch to arrange an appointment. Alternatively, call Robert on: 0330 222 2569, or 07850 240874.

You can also ask a number of national organisations for information and advice. Contact has a free helpline: 0808 808 3555 and Cerebra produces a Money Matters guide, which can be downloaded free at: https://www.cerebra.org.uk/help-and-information/guides-for-parents/money-matters.

**Work Capability Assessments**

If your child wants to claim Universal Credits at 16, they may have to have a Work Capability Assessment. This places people in one of the following three categories:

- fit for work
- limited capability for work - you
can’t work now, but you can prepare to work in the future, for example by writing a CV

- limited capability for work and work related activity – you can’t work now and you’re not expected to prepare for work in the future.

If your young person is severely disabled and it is decided that they have limited capability for work they will get the limited capability for work and work-related activity component of Universal Credits.

**What if your child can’t manage their own money?**

A young person can claim benefits in their own right, even if they need someone else to act on their behalf. Awards for DLA are usually reviewed in the five months before a child reaches 16. PIP can be claimed once a young person is 16. Claiming PIP at 16 is often the first time young people have to think about their ability to manage significant amounts of money.

In reality, most disabled young people don’t feel ready to take on this responsibility and ask their parents to look after their money for them, pay their bills and give them an allowance. This means parents take on the role of ‘appointee’.

An appointee acts on a young person’s behalf in all benefits matters, not just PIP. This includes telling the Department of Work and Pensions (DWP) about any changes in their circumstances, banking benefit money for them and using it in their best interests.

Before an appointee is agreed, the DWP will arrange to visit both a disabled young person and the person (often the parent) making the application to act on their behalf. The DWP has to agree that a young person is not able to act on their own behalf.

If you haven’t had a letter from the DWP to ask whether you will be your child’s appointee, call a few months before your child turns 16.
Tips for planning ahead

• Talk to your child about the pros and cons of managing their own money and how much of it they want to practise budgeting with. Agree how it will be split: how much will be pocket money, how much they will contribute towards the help you give them and what they will save.

• When you arrange the DWP visit, make the representative aware of your child’s communication, learning, or mental health problems and whether they’re careless about money or vulnerable to financial abuse.

‘I reminded Alex about last month when he’d raided his savings and spent £80 in an hour on the pier buying rides and fish and chips for ‘friends’ and how angry he had been that he couldn’t get the trainers he’d been saving for. We all agreed it’s best that I manage his DLA for another few years.’

What should your child pay towards their care?

Once your child starts claiming benefits, it’s a good idea to agree how much they will contribute to the household bills and how much they’ll pay towards the care you give them, and other stuff like running them around in the car. This way any changes in either of your financial circumstances shouldn’t leave you out of pocket and the young person will get a better idea of how much it costs to live and how far their money goes.

Personal Independence Payment (PIP)

In our partner title, Making Sense of it All, we cover applying for DLA for younger children in detail, but we have also included a brief DLA guide in this chapter for readers who have a recently diagnosed child in their early teens – see page 122 onwards.

If your child is almost 16 and you wish to claim for the first time you will be asked to apply for PIP.

Likewise, if your child has been receiving DLA, you will be sent a ‘hybrid’ adult DLA claim pack about seven months before their 16th birthday.
What is PIP?

Personal Independence Payment or PIP is a new benefit for people over the age of 16 who face extra challenges carrying out everyday activities or getting out and about.

Like DLA, PIP is not taxed or counted as income for means-tested benefits. It’s not based on National Insurance contributions and can be paid both in and out of work.

Special Rules

If a person is diagnosed with a terminal illness and is unlikely to live more than six months, they can claim PIP under Special Rules.

Though claiming benefits is likely to be the last thing on your mind if you’ve just been told your child has such a poor prognosis, it is a good idea to try to claim it on their behalf as soon as you feel able; PIP can’t be backdated to before the day you actually claim it, even in such distressing circumstances.

Claiming PIP under Special Rules means that you don’t have to wait three months and don’t have to fill in the ‘How your disability affects you’ form. Instead, if you call the dedicated team on the number below, they will ask you some questions. You won’t have to attend a face-to-face assessment, either.

If PIP is awarded on these grounds, a young person will automatically be awarded the high rate care component. To claim under special rules, call the dedicated team at the DWP on: 0800 917 2222.

Claimants are asked to get a medical report to send in for their claim. Ask your child’s consultant for a DS1500 medical report. If you’d rather not read what they write, ask for the DS1500 to be handed to you in a sealed envelope, or you can ask them to send it directly to the DWP for you.

A passported benefit

Like DLA, PIP is a passport to disability premiums. If you are still claiming legacy benefits, this
will be in the form of extra Child Tax Credits.

Under the new system, if a young person is included in your Universal Credit claim, a disabled child premium will be payable, on top of any child allowances.

Under Universal Credit, benefits are capped at around £20,000 a year, but for households who have a person claiming PIP this cap does not apply.

If a young person is entitled to the daily living component of PIP, then someone else may be able to claim Carer’s Allowance for looking after them. Getting the higher rate of the mobility component will entitle a young person to access the Motability scheme and a Blue Badge (see Chapter 11 for more on this).

What’s different about PIP?

**PIP is paid in two parts:** a mobility component based on a young person’s ability to get around, and a daily living component based on their ability to ‘look after themselves’.

Each component of PIP will be paid at one of two rates known as the standard and enhanced rate: the DLA care component currently has three. Realistically, this means that if you are already getting the lower rate of the care component, you are more likely to be at risk of being turned down for PIP. The weekly payment rates for PIP are the same as the rates payable for DLA.

**DLA rules allow for some people with certain conditions to automatically qualify for DLA components at specific rates. Under PIP no-one, (other than people who are terminally ill) will have any automatic entitlement.** Nearly all awards will be time-limited, with very few indefinite awards. It is likely that most awards will be shorter and reviewed more frequently than awards for DLA.

**PIP includes a broader range of practical skills than were included under DLA.** For example handling money, understanding how much change to expect and budgeting are new key tasks.
PIP shines a torch on social skills: asking about the person’s ability to mix and get on with others. It’s easier to know where to include how a young person struggles to ‘read’ other people’s intentions or understand how what they say and do can have an impact on how others feel towards them.

There is no page to fill in on night-time needs. Under DLA rules, no matter how dependant you are on other people to do things for you throughout the day, if you sleep through the night, you would only ever be entitled to the middle rate of the care component. And if you have a severe learning disability and challenging behaviour, under DLA you can only ever be awarded the higher rate of the mobility component if you are also up at night.

PIP uses an entirely new set of criteria, a points-based system, to decide whether someone qualifies for the benefit, and if they do at what rate they will be paid. For most young people the new assessment process will also involve a face-to-face meeting with a health professional. This will be covered later in the chapter.

When will a young person need to claim PIP?

If your child is 16 or over and they have never claimed DLA, they will need to claim PIP. If your child is over 16, and you report a change in ‘circumstances’, which might affect the rate of their DLA award, they will be reassessed under PIP.

If your child is rising 16 or they are over 16 and their existing DLA award is coming to an end, but you have not been sent a DLA renewal form, you’ll get a letter to tell you when and how to apply for PIP.

You cannot apply for PIP until your young person is 16, so there will be special arrangements allowing current DLA awards to run on after your child’s birthday, until a decision is made on their PIP claim. We understand these claims will be looked at by a specialist team of decision-makers.
You can choose to make an application for PIP even if your child has an indefinite award of DLA. This would make sense where a young person is likely to be awarded a higher rate under PIP than their current DLA award. For example if they have high support needs throughout the day but not at night.

As appointee, you need to act promptly as soon as the Department for Work and Pensions (DWP) writes to you or your child about PIP. If neither of you reply to the invitation to apply for PIP, their DLA award will be suspended four weeks later. If a claim is made within four weeks after the suspension, the DLA award will be restored until a decision is made on the PIP claim. If you do nothing during the four weeks suspension, your child’s DLA claim will end permanently eight weeks after they wrote to you. There will only be limited appeal rights against this decision.

**How to start a claim**

PIP claims begin over the phone.

Ring the Department of Work and Pensions (DWP) on: 0800 917 2222. You can call on behalf of a young person, but they should be with you when you do this.

It’s worth getting organised before you ring. You will be asked for basic details like your child’s name, address, date of birth and main area of difficulty. You will also need to give your child’s National Insurance number, their doctor’s or health worker’s name and have information to hand about time your child has spent abroad, in a residential school, care home or hospital. The DWP will also ask for bank or building society details.

As long as a young person has had the additional needs for at least three months, expects to have the same needs for at least the next nine months and meets the residency test, they will be sent a ‘How your condition affects you’ form. The claim pack is personalised. It comes with notes to help you fill it in.
Making a strong claim for PIP

PIP uses an entirely new set of criteria, a points-based system, to decide whether someone qualifies for the benefit, and if they do at what rate they will be paid. To make a successful claim for PIP, a young person needs to score eight points to qualify for the standard rate of component. 12 points or more qualifies them for the enhanced rate.

This new type of assessment will focus on a young person’s ability to carry out everyday activities. There are ten daily living activities and two mobility activities and a set of descriptors for each: what a young person scores against each activity should reflect the difficulty they experience in the following areas:

- preparing food
- eating and drinking
- managing treatments
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating verbally
- reading and understanding written information
- mixing with others
- making decisions about money
- planning and following journeys
- moving around

The number of points a young person scores in the last two categories will determine if they get the mobility component, and at which rate. Scores in the other categories will determine whether they get the daily living component.

Each activity has a list of descriptors that carry different scores. Some activities attract more points: speaking, eating, and planning a journey carry more weight than activities like budgeting, planning a meal and washing.

You can only be awarded points for one descriptor in each activity, so it’s worth giving as clear a picture as you can. To get any points for an activity, you need to satisfy at least one of the descriptors for at least 50 per cent of days.
The new assessment prompts you to explain the challenges a young person faces doing a task safely, to an acceptable standard, as often as they need to, as well as the individual way they tackle a task when they don’t have someone to help and have to ‘get by’. It’s important to focus on these prompts.

Tips for claiming PIP

- Do your best to ‘tell it how it is’. Young people are often the ones who know how their illness or disability affects them, and most will be invited to a face-to-face assessment, so think about how you can involve them in making the claim.
- Gather evidence: advice, assessments and/or reports, from health, education or social care practitioners. If your child has an EHC Plan, make sure you have a copy. Include as much supporting information as you can with the claim.
- If possible, send extra evidence to support what you’re saying. Copies of things like diaries, medical reports, speech and language assessments and EHC Plans are often useful. These may help to persuade a decision-maker.
- Make photocopies of everything you send (both the claim pack and any extra evidence) you will need to refer to them if you want a decision looked at again, or when the claim is reviewed.
- Keep copies of everything in a safe place— you may not have any paperwork returned to you before a face-to-face interview. It can also help you the next time your child’s PIP is reviewed, as they may have left school or college, and evidence of their level of need and abilities will be harder to come by.
- Think about returning your claim by Special Delivery. It protects you from the claim getting lost in the post, or the DWP saying they haven’t received it. You get a receipt for Special Delivery items from the Post Office and the DWP has to sign to say they’ve received it.
PIP applications are time-consuming and detailed, so it’s worth getting help to fill them in. Disability Rights UK has a very helpful guide to making a PIP claim. It includes the scoring system for the twelve activities. You can download it at: www.disabilityrightsuk.org/personal-independence-payment-pip.

Unpicking the jargon: what counts as help?

- You will be assessed as able to carry out an activity ‘unaided’ (and that means score no points for it) if you can carry it out ‘without the use of an aid or appliance; or supervision, prompting or assistance.’ These terms carry very specific meanings within PIP regulations.
- ‘Assistance’ means physical ‘hands on’ help: it does not include spoken encouragement or explanation.
- ‘Supervision’ means the ‘continuous presence of another person for the purpose of ensuring (the disabled person’s) safety’.
- ‘Prompting’ is ‘reminding, encouraging or explaining to another person’: it doesn’t explicitly require the presence of another person, but must be essential for the activity to be carried out’. So, for example, the other person might be at the other end of the phone.
- ‘Aid or appliance’ is any device that improves, provides or replaces a disabled person’s impaired physical or mental function; and includes prostheses. Examples might be adapted cutlery, modified kitchen utensils, a standing frame, communication apps, grab rails. They count even if the claimant doesn’t use the aid but could be ‘reasonably expected’ to use one but does not for reasons of cost, availability or cultural reasons.
- ‘Unaided’ also relies on a disabled person being able to carry out the activity ‘in a way that is safe and reliable, does not take too long and can be repeated as needed. If they cannot do so, another descriptor must be chosen and ultimately the
individual may be considered to be unable to complete the activity at all.

Don’t leave it up to an assessor to have to guess! It’s always worth giving a very detailed account to explain what happens in reality. For example, to get the higher rate of the mobility component, and score 12 points on grounds of physical impairment alone, you will need to provide evidence that a young person who ‘can stand and then move a metre, cannot move more than 20 metres, either aided or unaided’. This seems a really tough test, especially as the distance under DLA to get the higher rate of the mobility component was 50 metres.

The next descriptor, that a young person may be able to walk more than 20 metres but no more than 50 metres, only scores 10 points. This is not enough to get the higher rate under PIP, or access the Motability scheme or a Blue Badge. Remember though, this descriptor can only be applied if a young person can do this safely, to an acceptable standard, repeatedly and in a reasonable time. If you can explain how a young person cannot meet one or more of these additional requirements, it is likely that you can reasonably argue the descriptor that best fits is the one that attracts 12 points.

‘Zoe has cerebral palsy. She can walk 40 metres with a walking frame, but to do this she needs to draw on all her resources. The physical and thinking effort of getting her body to do what she wants is exhausting. Just this short distance takes her at least five minutes. The first 20 metres takes her two minutes but the next 20 metres takes at least three minutes. Then she needs to stop and rest. She needs to be able to sit down and take a break for at least five minutes. On a bad day she would need a longer rest. This means on a good day it will take Zoe 15 minutes to walk 80 metres. Even on a good day, Zoe would not be able to repeat this more than twice, on another day she may only be able to repeat this once. On a bad day Zoe may not be able to repeat this at all. Any amount of walking has an impact later in the day. If Zoe has been out in the morning, she will need to sleep most of the afternoon to recover.’
This means that at best, using her walking frame, Zoe may be able to walk 160 metres, but it would take her 35 minutes. Then she would not be able to walk any further for several hours. So on a good day, it would take Zoe at least 155 minutes to walk 161 metres. It could be argued that Zoe cannot maintain this level of activity ‘repeatedly’ or ‘in a reasonable time’. She certainly cannot do it even once without her walking frame.

If a young person has good and bad days, it’s really helps to explain this too. Describing exactly what they can do two days out of seven and what they can manage on the other five helps the assessor work out which descriptor (and so how many points) best reflects a young person’s abilities. Points will be awarded for the descriptor that best fits 50 per cent of the time.

As with DLA, PIP claims are less likely to be successful if you don’t use the opportunity to give examples. Many of us have found that we’ve had to add additional sheets of paper to explain the help our child needs in sufficient detail. The clearer the picture you can give, the less likely it is that a young person will be called for a face-to-face assessment.

If you feel stuck with a PIP claim pack, download the Disability Rights UK Guide to claiming PIP at www.disabilityrightsuk.org. It is comprehensive and has useful examples.

Contact also has a fact sheet on claiming PIP, as well as a guide that can be downloaded as a PDF. Go to: https://contact.org.uk and select ‘advice and support’, then click on ‘benefits and financial help’.

**Face-to-face assessments**

It is very unlikely that severely disabled young people will be asked to attend a face-to-face assessment. Nevertheless, to avoid unnecessary interviews, be sure to send as much supporting evidence, and give a detailed account of how they cope with daily activities, their communication or access needs.
Most other young people will be required to attend a face-to-face assessment. For most claimants and especially disabled young people, this is likely to feel overwhelming. There is a lot you can do to make this a fair and a positive experience.

A young person should always have someone to support them and may need help to think about who is the best person to ask. It needs to be someone who is both ‘on their side’ and understands how their disability impacts on everyday life. This can be a friend, support worker, or health, education or social care practitioner. Most often this is likely to be you, their parent carer. It’s really worth preparing for this meeting. Start keeping a diary so you can illustrate what your child can do and the help they need.

A young person may not have had much involvement in writing their PIP claim and, even if they have, the last time either of you looked at it will have been months ago. So read through it again, together. Spend a bit of time rehearsing: take turns asking and answering ‘open’ questions. ‘Can you tell me how you would make a cup of tea?’, ‘How did you get here today?’ but don’t practise too much.

Assessments may happen at your home or at an assessment centre. If you need to travel, plan how you will get to the venue. If a young person is very anxious it may even help to practise the journey and check out the building a few days before for things such as accessibility. Travel expenses will be reimbursed: keep receipts or note mileage if you come by car. Parking charges are covered, too.

On the day, arrive in good time. Make sure you are both as comfortable and feeling as calm as possible. We understand you can make a record of what is said at the meeting but you have to be able to give a copy to the assessor and it makes sense to say well in advance if you’d like to do this.

The healthcare professional who does the assessment will want to see for themselves how what is written on the PIP form matches
up with the young person they are meeting.

If a young person struggles to ‘follow’ the thread of a conversation or is likely to misunderstand what other people say, you will need to act if you notice this is happening. Doing this in a clear, positive way: repeating and phrasing questions more simply, using words they know, checking back they really understood the question and everyone else has understood what the young person is trying to explain will help the assessor to understand what the difficulties are.

Often a young person will have a very good idea about what is difficult for them and how they manage. But even so, some may say what they think the healthcare professional wants to hear. You will be able to add to and comment on what a young person says if you feel their own perception of their abilities is unrealistic. It helps to give real examples of occasions when a young person hasn’t had the help they needed and things haven’t gone well or routine daily activities didn’t get done at all.

It’s important the assessment goes at a comfortable pace and it’s okay to ask for a break, if a young person needs one. Be aware that the healthcare professional will observe and note everything: from whether a young person lets a door go in your face as you come into the room, to how they put their coat on.

If there is any sort of physical examination, a young person should not feel pushed to do more than they can safely manage or anything that is painful. Agree beforehand how they will tell you or signal that they cannot carry on.

Towards the end of the assessment, the healthcare professional should give a summary of their findings and ask if there are any questions or if there is anything more you would like to add. Later they will write a report and send it to the DWP.

The decision about whether to award PIP, at what rates and for
how long is made by the DWP. You will be contacted by letter about the outcome.

What happens if you do not agree with a decision?

The outcome letter will explain what to do next if you do not agree with a PIP decision and about time scales. The first thing to do is to contact the DWP, you can do this over the phone.

Say what it is that you do not agree with and why. It may be that you feel a young person should be entitled to the enhanced rate for the mobility component rather than the standard rate. Or maybe you disagree with the length of the award. Always be aware that when you ask for a claim to be looked at again, the DWP can look at both components as well as the length.

If no award has been made at all, you should get a phone call from the DWP to explain why. You should ask that another decision maker look again at the claim: this is called ‘requesting a re-consideration’. If you ask, the DWP must do this. Ask for copies of all the information, including any reports submitted by the healthcare professional. This can help you build a case. Say that you will write to give detailed reasons why you disagree.

Go through the paperwork carefully, note if there is any difference of opinion between what you put on the claim pack and the healthcare professional’s report, if any evidence has been disregarded or if you need to gather more reports to support what you say. Ask for extra time if you need it and say when you will write back to them. Otherwise a decision may be made straight away.

The right to appeal a PIP decision only arises once a different decision-maker has reviewed all the information and you have the outcome in writing. Hopefully, the first decision will be revised in your child’s favour and you won’t need to go to appeal. If it isn’t, all is not lost.
Whether or not the decision is changed, you will get a mandatory reconsideration notice. You will need this to appeal. You now have one calendar month to submit your appeal. Appeals are made directly to an independent tribunal. You will need to fill in a SSCS1 notice of appeal. You can download this from www.gov.uk website.

Say clearly what part of the decision you disagree with and why. Send it back within the timescale and make sure you keep a copy for your records.

You will get a pre-hearing questionnaire. It’s best to opt for a face-to-face hearing – your chances of a favourable outcome are much greater if you do.

You do not need to take someone like a solicitor to represent your young person. Experience of DLA appeal tribunals tells us that parents and carers are generally best placed to ‘tell it how it is’ and say it from the heart.

If you have any more supporting evidence, send it in at least a week before the hearing. If you only get a report the day before, take it with you and explain about this, as it is usually the case that the Tribunal panel will accept evidence on the day.

Hearings are informal and you will be able to comment on and add to what your child says. It’s always best to prepare again as you did for the face-to-face assessment with the healthcare professional.

Disability Living Allowance (DLA)

If your child is in their early teens and they have recently been diagnosed with or acquired a disability, you may want to consider claiming Disability Living Allowance (DLA). This is a benefit for children under 16 – if your child is almost 16, you will be asked to apply for PIP instead.

A DLA claim can be made if your child needs help looking after themselves, or they need watching over to stay safe, or if they find it difficult to walk about or get around because of a disability or chronic illness.
Like PIP, DLA isn’t taxed and income from DLA is ‘disregarded’. This means it’s not taken into account if you or your child claim other benefits. DLA is a ‘passport’ to other sorts of financial help too. If you claim other benefits because you are on a low income, it’s always worth saying your child gets DLA: there can be extra benefits for parents.

It’s best to get the DLA claim pack from the DWP as they will date stamp the form. As long as you get the completed form back within six weeks, a successful claim will start from the date you requested the pack.

**Making a successful DLA claim**

To make a successful claim for DLA you need to show a disabled child ‘requires’ substantially more ‘attention’ in connection with their ‘bodily functions’ than is usually required by an adult; or ‘continual supervision to avoid substantial danger’ or someone ‘to be awake for a prolonged period or at frequent intervals’ at night to ‘watch over’ them.

**What does all the jargon mean?**

- **‘requires’** does not mean medically require, it means reasonably require. For example, a young person with a speech and language disorder may have a reasonable requirement for attention from another person to make themselves understood and make sense of what others are saying.
- **‘attention’** is help from another person to do the personal things a young person cannot do for themselves.
- **‘bodily functions’** are anything to do with how the body works and what it does.
- **‘continual supervision’** means a young person needs someone around to minimise the risk of them coming to harm, or putting others in danger.
- A **‘prolonged period’** is at least 20 minutes.
- **‘frequent intervals’** means at least three times a night.
- **‘watch over you’** means someone is awake and alert and getting up to check on a young person.
What counts as ‘bodily functions’?

There’s a very long list of what counts as bodily functions: breathing; hearing; seeing; talking; listening; signing; reading; eating; drinking; walking; sitting; maintaining good posture; sleeping; turning; changing bedclothes in the night; eliminating waste products; getting in and out of bed, a bath or chair; washing; shampooing hair; cleaning teeth; brushing hair; dressing and undressing; help with medication or therapies; managing feelings and behaviour; thinking; problem solving; making choices; being prompted, reminded or encouraged.

What counts as ‘attention’?

All sorts of things count as attention (or help), including:

- The resourcefulness, time and energy you put into helping your teenager learn what other young people seem to pick up effortlessly, including problem-solving when unexpected things happen.
- Practical and hands-on help, or prompting and encouragement with everyday activities like dressing, washing, and toileting, cooking or even getting along with other people.
- The thinking you do to anticipate and manage potential difficulties.
- The ways you adapt your communication: some disabled young people need help to make themselves understood, make sense of what’s going on around them, or to manage difficult feelings like anger or anxiety.
- Nursing or therapeutic help: monitoring a young person’s medical condition, giving medication, helping a young person use special equipment or carry out a therapy programme.
- Help to get out and about and to keep safe.

Don’t underestimate the help your child needs. Some young people need much more help than others. Even if your child needs extra help with just some of the things we have mentioned, we think it’s worth making a claim for DLA.
If your claim is successful, DLA is payable in two parts – ‘care’ and ‘mobility’ components.

**The care component of DLA**

A child can claim this if they need help with ‘personal care’ or looking after themselves. This includes things like keeping safe and communication, as long as they have needed the extra help for at least three months and will continue to need the help for at least another six months. There are three rates at which the care component can be paid.

**The low rate**: if a young person needs some help for a significant portion of the day and/or they cannot prepare a cooked main meal for themselves.

**The middle rate**: if a young person needs frequent help or constant watching over to stay safe or keep others safe during the day. Or some help or watching over at night.

**The high rate**: if a young person needs help day and night.

**The mobility component of DLA**

A young person can claim this if they need extra help with getting around. There are two rates for this:

**The lower rate**: if a young person needs someone around to keep them safe, or someone to help them find their way around.

**The higher rate**: if a young person’s ability to get around is severely restricted because they:

- Cannot walk at all, or are virtually unable to walk.
- Have no legs or feet, or walking would be dangerous for their health.
- Have the most severe visual impairment or are deaf and blind.
- Have severe learning disabilities affecting both cognitive and social functioning and/or disruptive behaviour that is unpredictable and regularly requires physical intervention to prevent injury. They also need to be getting the high rate of the DLA care component.
To get the high rate for mobility, young people are likely to have a severe physical or sensory impairment; a life-threatening neurological, cardiac or respiratory disorder; or the most severe autism or learning disability and challenging behaviour. If a young person is awarded the higher rate for mobility:

- The vehicle used by the disabled child may be exempt from Road Tax.
- A child will be entitled to a Blue Badge. This should make it easier to park close to the places they need to go.
- The child or their appointee may be able to buy or lease a car or purchase an electric wheelchair through the Motability scheme (see page 210 for more information).

If you don’t agree with any part of the DWP’s decision (a non-award, the rate of either the care or mobility component, or the length of the award), you need to act quickly. There are short timescales for challenging decisions, so get advice as soon as possible.

Getting help with claiming DLA

The county council runs a benefits advice service for families or carers of young people with special needs. They can help with form-filling, reviews, appeals and tribunal representation. All welfare benefits are covered by the service, including DLA. For further information, call Robert Hayes on: 0330 222 2569, or 07850 240874, or email: robert.hayes@westsussex.gov.uk.

Many other disability organisations offer useful advice about claiming DLA for children and young people with specific illnesses or disabilities. For example, the National Autistic Society (NAS) has information that will help you if your young person has an autistic spectrum condition and Cerebra also produces a guide to claiming DLA.

Carers Allowance (CA)

Carers Allowance (CA) is a weekly payment for anyone who spends at least 35 hours a week looking after someone with an illness or disability, but isn’t paid to do it.
The person they look after must be getting the middle or higher rate of DLA or either rate of the daily living component of PIP.

If someone other than you cares for your teenager, they can claim the benefit instead. Even if your child is at school or college, many parents will ‘clock up’ more than the required 35 hours a week. Only one person can claim CA for your child and you can only claim CA once, even if you care for more than one person who’s getting DLA or PIP.

You can claim CA and earn up to £120 a week after deductions (tax, National Insurance and other allowable deductions). This amount is revised every April and is correct for the year 2018/19. Up to half your earnings can be disregarded if you pay someone who’s not a ‘close relative’ to look after your child. You can claim CA even if you are getting PIP or Attendance Allowance yourself. CA is taxed and counted as income if you claim other means-tested benefits.

It’s worth claiming CA even if you are on means-tested benefits because although CA is deducted from them, claiming it protects your pension and makes you eligible for a Carer’s Premium, so the amount of means-tested benefits you get will increase.

The process for claiming CA is simple and quick. Call the Carer’s Allowance Unit on: 0800 731 0297, (Textphone: 0800 731 0317) for a claim pack, or claim online at: www.dwp.gov.uk.

Other sources of financial help

See Chapter 11 for details on travel and transport schemes and concessions, including Motability. For information about Direct Payments (DP) and funding for adaptations in the home, see Chapter 10.

Once your child is 18, you may be able to apply for a Carers’ Grant from the council. It can help if you want to take a break and need a temporary increase in a care package, or a short stay somewhere else for your son or
daughter while you’re away. The grant can also help towards the cost of a holiday, travel costs, days out with the person you care for, or for leisure, adult education, or support to help you stay in employment. You’ll need a carer’s assessment to be eligible, see page 151. Call the Adults’ CarePoint on 01243 642121 (Text Relay: 18001 01243 642121) or email: socialcare@westsussex.gov.uk to ask for one.

Some charitable organisations make grants for specific purposes like holidays or buying a special piece of equipment. You’ll find details in a directory called A Guide to Grants for Individuals in Need, which should be available in bigger libraries.

Further help with disability benefits

Organisations such as the Citizen’s Advice Bureau can offer similar benefits and financial advice and support to disabled adults or their carers.

Disability Rights UK is a national charity committed to breaking the link between poverty and disability. It publishes The Disability Rights Handbook: a comprehensive guide to benefits and services for disabled people, their families, and carers. Be warned that it’s not light reading and is also updated each year, so unless you have a special interest in benefits, it’s probably best to look for it in the reference section at your library.

Financial planning, wills and trusts

Perhaps one of the hardest parts of being a parent carer is knowing that one day you won’t be around to look after your child. It is natural to worry about what will happen to them and how they will cope without you, especially if they have a disability that means they are unlikely to live independently.

One of the most important things any parent can do is to ensure that they have make a will and that they have named a guardian, in case anything
happens to them before their child(ren) reach adulthood. It’s easy to assume that this is all that needs to be done, but if you have a young person with a disability, it’s not quite as straightforward.

Even if your child might manage their own money, there is also the need to consider that their disability could leave them open to financial exploitation by others. Leaving your child money or property could also prevent them from claiming means-tested benefits.

Some families think they can cover this by leaving all their money to the sibling of their disabled child. They assume that an informal agreement in which the sibling promises to look after the disabled person for the rest of their life will be enough. But this is a risky idea, as, officially, the money would be the sibling’s. If they die first, get divorced, or simply decide that they have changed their mind, your disabled child could be left without a penny.

What can you do?

In order to ensure that your disabled child is provided for, you may want to consider setting up a trust. This is a formal legal agreement that sets out what will happen to your assets (your money and property) after you die and how the money will be used to benefit the disabled person.

A trust has two or more people, called ‘trustees’ who hold the money on behalf of the disabled person, who is called the ‘beneficiary’. The trustees are named in your will.

When your will is written, you also write what is known as a ‘letter of wishes’, which explains to the trustees how the money should be used. For example, you may want to include the sorts of activities that your disabled young person enjoys and the therapies and services that you would like them to benefit from, using the money in the trust.

When it is first set up, you may be asked to make a small payment
(usually of around £10) to open it. The trust will only become fully active once you have died and your assets such as your savings and money from property is added.

You can find out more about wills and trusts through Mencap, who can also signpost you to experienced solicitors locally. Call: 020 7696 6925 or email: willsandtrusts@mencap.org.uk.

To ensure that you choose the right type of trust for your young person it is important that you choose a solicitor with the right qualifications and experience. This is a highly specialised and complex area of law, so we suggest that you check that the solicitor is a member of The Society of Trust and Estate Practitioners (STEP): www.step.org or call: 020 3752 3700.
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. But if your child needs a lot of support now it can be hard to find the headspace and time to think about the future. It is worthwhile if you can, though.

‘You know how it is, you deal with the short-term because the long-term is just so difficult to imagine.’

This chapter explains social care assessments for disabled adults and how they are carried out. It also covers the range of services that may be available and how those services are paid for.

Who gets support from adult social care?

‘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.’

There have been significant changes to the law regarding special educational needs and social care provision for children and young people with SEND. Preparing for adulthood is a key element of recent law reforms. For young people aged 18 to 25, there are two pieces of legislation that mean they may be entitled to support from adult social care.

The first is the Children and Families Act 2014, which 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 (see Chapter 1 for more on EHC Plans). In addition to this, Part 1 of the Care Act 2014 deals with the care and support of people over the age of 18.
Both the Children and Families Act and the Care Act 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 4)
- coordinated assessments and Education, Health and Care Plans
- personalisation and personal budgets.

Not all young people who received social care support when they were young will qualify for adult services, and having an EHC Plan does not necessarily mean that your young person will be entitled to social care support as an adult. However, it’s also important to highlight that some young people who may not have had support from social care in the past may need social care support in adulthood. This is why it is important to have an assessment done. For more on this, see facing page.

Moving to adult social care

Once your child is 18 years old, the social care support they need is provided through the council’s Adult Social Care Team. Adult social care workers carry out needs 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 young person. In West Sussex enquiries are initially directed through the Adults’ CarePoint on: 01243 642121, or email: socialcare@westsussex.gov.uk.

If your child has an EHC Plan 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. It is helpful to invite someone from social care to transition planning meetings, as they will decide whether your child is likely to need or get support from the local authority in the future.

If your child doesn’t have an EHC
Plan but is getting social care support you should speak to your social worker about moving to adult social care.

‘Rachel’s transition from Children’s to Adult Services has been very smooth. I feel that the different agencies … 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.’

Working together

A successful transition to adult care and support involves the young person, their families and professionals working together. The Care Act 2014 means local authorities have a legal responsibility to cooperate, and to ensure that everyone works together to get the transition right.

Child’s Need’s Assessments

Under the Care Act 2014, local authorities now have a duty to carry out a Child’s Needs Assessment (CNA) for a young person, where there is ‘likely to be a need for care and support post-18’. The purpose of the assessment is to find out what adult social care a young person might be eligible for once they reach 18, so he or she can make informed choices about the future.

When does planning start?

Under the Care Act 2014, young people or their parents can request a Child’s Needs Assessment (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. It should include an ‘indicative personal budget’, so that young people are able to plan what their future support might look like. You can read more about personal budgets on page 142.

If the local authority thinks your child will not need adult care social support, or they believe you are asking too early for a Child’s Needs Assessment (CNA) to be useful, they can refuse to
carry out the assessment. If they do refuse, they must explain why in writing and include information and advice on what can be done to ensure the young person can avoid the need for care and support.

If the local authority does not carry out an assessment because the timing is not of ‘significant benefit’ they should advise you when the CNA should be carried out and contact you and your young person to arrange the assessment when that time comes.

For a young person with an EHC Plan, the conversation about whether they need a Child’s Needs Assessment 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, it is a good idea to ask their social worker at their next review when it will be useful to have the assessment done.

What should the Child’s Needs Assessment (CNA) include?

The assessment should be person-centred (see page 282) and it should give information about your child’s needs, plans and aspirations for their future. It should have clear short and medium term outcomes so that it can then be used as the basis for a conversation with: your young person; you; a professional from adults’ services (who should have good knowledge of support options that will be available to your child); and other professionals involved in the young person’s care and support.

Under the Children and Families Act 2014, EHC plans must clearly set out the care and support that is required as a result of the young person’s special educational needs. So if a young person is over 18 and they have 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 SEND and specify
other care and support. It should clearly highlight which elements are not directly related to SEN.

**Eligibility and the Assessment Process**

Since the Care Act came into force, it has changed the way the local authority 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. They will look at strengths and capabilities and identify support that may be available in the local community to help your young person be as independent as possible. They will ask you about:

- managing and maintaining food and drink
- managing personal care – making sure they are clean and dressed appropriately
- managing toilet needs
- getting around the home safely
- looking after the home
- developing and maintaining personal relationships
- being able to access and take part in work, training, education or volunteering
- using services in the local community, such as public transport and leisure facilities
- carrying out caring responsibilities

The local authority may measure your young person’s needs against other ‘outcomes’ too – so ask what these might be.
They also look at their care and support needs over the last year to consider whether your young person’s needs may change.

The local authority 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 local authority think that their needs will not be eligible. To arrange a needs assessment if your young person is already 18 or, if they are under 18, a Child’s Needs Assessment (CNA), contact the Adults’ CarePoint and request an ‘Assessment of Needs’.

The assessment process

During the assessment, a social care worker will gather information from your young person, their parent carers and relevant workers from education, health and social care. Assessments are usually done in your home and may take more than one visit.

The social care worker doing the assessment should note down what is said during the meeting. This should include the services your young person needs and also anything that you disagree with.

It is important to involve the young person as much as possible during the assessment process. They may need specialist support to help them communicate their thoughts and feelings – for more on helping your child to communicate effectively, see Chapter 2.

What happens after the assessment?

If 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 plan will outline the young person’s and carer’s needs and the support that is required, then social care will work out how much funding is available to help you with this.

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 care – read more about personal budgets on page 142.
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, as well as advising on how to prevent further needs developing.

Assessment tips

- Don’t assume because your child has an EHC Plan that 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.
- Don’t be afraid to ask questions and explore different options. When you are speaking to professionals, make sure you note down their name, job title and contact details, in case you need to go back to them.
- Don’t be afraid to suggest things that haven’t been tried before. If you can explain why your idea may work others may be willing to listen.
- Don’t see professionals as the ‘opposition’. 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 the next steps are and when they will happen.

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 2014 requires them to continue providing him or her with that support through the adult 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.

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 this will be done. The plan should be reviewed on an annual basis.

The person from social care 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, West Sussex County Council or community and voluntary organisations.

How a support plan works

Your social worker will discuss how your young person’s needs can be met with you and your young person (if appropriate). 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 child 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 young person. If you feel anything is incorrect you can ask staff to change this.

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

**Things to remember**

When you get a copy of your child’s support plan, double check 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 being monitored properly, contact the Adults’ CarePoint and request a review date.

‘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.’

**Keeping the support plan up to date**

Completing the planning process and putting care and support arrangements in place 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, although the Care Act does not specify how often this has to happen. But if anything has changed, a new assessment must
be carried out, so it is important to let the local authority know about any changes as quickly as possible. Your young person also has a right to request a review of their care and support plan, if they wish.

**What if you don’t agree with the assessment findings and support plan?**

If you don’t agree with the findings of the assessment, contact the Adults’ CarePoint 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. If you or your young person needs support to do this they could ask for help from one of the advocacy services in West Sussex (see pages 30 and 36 for details).

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 care worker 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 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 the Adults’ CarePoint.

‘**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 Care Act 2014 gives local authorities the power to charge people for social care services. This includes services such as residential care homes, short breaks, day services, home care, community support, and home adaptations.

Depending on your young person’s financial situation they may be asked to pay towards the cost of their support, which the Local Authority will help to arrange. This might come as a surprise, but be aware that very few people have to pay the full cost of their care. The amount payable will be 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 Local Authority 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 (for more on mental capacity see page 29).

Financial assessments

A financial assessment is carried out alongside your young person’s needs assessment. The assessment will work out how much the young person will have to pay towards a service and how much the council will pay. It takes into account the young person’s financial position and is also used to check whether they are getting the correct state benefits. The mobility component of DLA (Disability Living Allowance) (PIP if over 16) should not be taken into account when the young person’s income is assessed. If the service is for your young person, your own finances should not be taken into account.
Young people should not have to pay for services if they are 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.

**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.

**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 (this could range from all of the total to nothing at all).

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.

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 18.
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.’

**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, often known as a ‘personal assistant’ (PA), to care for your child, 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 West Sussex County Council – these would be arranged separately as part of the personal budget, as you cannot purchase their services directly.

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 arrange and pay for services for their child. Young people over 16 can take responsibility for direct payments or, if they are 16 or 17, choose to share the 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 manage 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 authorities must tell you about direct payments and support you if you want them. If
you’re already getting services, your child’s social worker should already have told you about direct payments.

**Why choose Direct Payments?**

Direct payments are worth thinking about, especially 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 would most 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.

Independent Lives has a website with advice on everything from direct payments to personal budgets and employing a PA. For more information go to: www.independentlives.org or call: 01903 219482.

**What support is available to over 18s?**

The way adult social care support is provided 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 Adults’ CarePoint call 01243 642121, or email socialcare@westsussex.gov.uk for more information.

Find out about the adult social care support provided in West Sussex on the Connect to Support website at: www.westsussexconnecttosupport.org. It also has advice for carers as well as information about support groups, voluntary organisations, charities and more.
Finally, the Local Offer contains information about all sorts of local services including health and social care. For more information on the Local Offer go to page 4.

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, talk to them, or call the Adults’ CarePoint on 01243 642121 for more information.

Day activities

Day activities refer to a range of provision. 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 centres 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.

The following list is correct at the time of going to press. We recommend that you check: www.westsussexconnecttosupport.org or the websites posted below to see what’s available in your area and on which day and time as these could be subject to change. For entries marked ‘*’ your young person will need a social care assessment to access the service.

- **4Sight** clubs and specialist groups offer social opportunities for people with sight loss. For more, go to: www.4sight.org.uk/clubs.
- **The Aldingbourne Trust** runs a number of drop-in sessions, activities and clubs, as well as My Network, which is an information, advice and guidance service. All are designed to help adults
with learning disabilities and/or autism to reach their full potential with tailored support. For more, go to: www.aldingbournetrust.co.uk.

• **The Apuldram Centre**, Chichester, has a day centre that enables working age adults with learning disabilities to take part in a wide range of occupationally focused and enterprising activities such as: horticulture, woodwork, cookery, arts and crafts. It also runs ‘hub club’ with various activities. See: www.apuldram.org/hub/

• **Burnside Day Services**, Burgess Hill. Offer activities linked to training, work, independent living and leisure opportunities, such as: travel training, road safety, independent living skills, and money management.

• **Chailey Heritage Foundation** runs Futures Hub, which offers day provision to young adults aged 16+ with disabilities including physical and complex health needs. It offers the chance to develop life skills, develop a peer group and to live life to the fullest. Young people can access the Futures Life Skills Centre, which offers art, cooking, drama, and other multimedia and sensory activities. There is also a fully accessible gym, spa, and hydrotherapy pool. For more, go to: www.chf.org.uk/futures-hub.html.

• **Chestnuts Day Centre**, Bognor, **Glebelands Day Centre**, Shoreham, **Glen Vue Day Centre**, East Grinstead, **Judith Adams Day Centre**, Chichester, **The Laurels, Day Centre**, Rustington, **Maidenbower Day Centre**, Crawley, are for people with dementia and or longer term/complex social care needs. The centres are mainly used by older adults, but take younger people if they can meet their needs. Activities include arts and crafts, cooking, music and games.

• **Dimensions Outreach 3 Way** supports people with learning disabilities and autism. It runs a number of classes every week and also has a day
centre in Ifield, which runs groups and workshops.

- **Hollyrood**, Lindfield provides day centre services for people with autism aged 18+. They also support individuals with challenging behaviour or epilepsy. Facilities include a gym, woodwork centre, pottery and sensory room.

- **Millstone Day Centre**, Sayers Common offers day services for those aged 18+ with autism, learning disabilities, mental health issues and the elderly. Sessions offer activities such as cooking, IT skills, coffee mornings, Wii games, arts and crafts.

- **The Pines**, Worthing, is for adults with learning disabilities. They can support young people from local schools and colleges who are transitioning to adult services so they can spend time in the centre before they start. Activities include life skills, drama, dance and singing.

- **The Point, Scope West Sussex Day Centre**, Chichester, offers activities for people aged 18 to 50 years.

- **The Rowans**, Worthing is a specialised service for people with an acquired brain injury and/or physical disabilities and complex needs. A variety of activities are run including bingo, IT skills, cooking, drawing and gym.

- **Worthing and District Scope**, Worthing, has a day centre providing activities for adults with disabilities including karaoke, football, art, cookery and swimming.

**Tips for choosing day activities**

- Ask your social worker 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.

- Make sure that your young person also gets the chance to see the activities and look round the centres, too.
Short breaks or respite

Short breaks or respite care aims to give families who care for a family member some time out from caring. There are no rules about where short breaks take place, but it’s usually provided at other people’s homes, residential homes, or by people coming into your home or taking the young person out.

The Aldingbourne Trust has a service called ‘Support Workers Direct’ which matches the right carers with the families and individuals they support. The service offers personalised care packages at home, in the community and respite support. For more information go to: www.aldingbournetrust.co.uk 01243 837866 or email: juliew@aldingbourne.org.

Outreach 3 Way provides short breaks and respite to people aged 18+ with learning disabilities and/or autism. For more information email: Tracy.Farrow@dimensions-uk.org or go to: www.dimensions-uk.org/short-breaks-respite-queens-lodge-west-sussex. 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 Care offers daytime and evening care in your own home, either temporarily or regularly. For more, go to: www.crossroadscare-sc.org.

You can also arrange your own support, through an Individual or Personal Budget or Direct Payments (see pages 142 to 144).

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.

Now, home care services help only with personal care such as washing and bathing, getting up and dressed or getting ready for bed. Adult social care has a small ‘in-house’ care service, but most care needs are mostly provided by private agencies, all of whom are registered with the Care
Quality Commission. You can read more about the services available on West Sussex’s Connect to Support website at www.westsussexconnecttosupport.org.

**Personal Assistants (PAs)**

Some people assessed as needing home care services choose to get Direct Payments (see page 143) so they can employ their own Personal Assistant (PA).

A Personal Assistant is someone who provides support to disabled children and adults. They may offer support with every day activities such as shopping, leisure activities, washing and personal care.

Your young person may have a Personal Budget to pay for the support they need (see page 142). In West Sussex, Independent Lives has a website with advice on employing a PA. You can advertise for a PA on their vacancies board, or use their online database of PAs to find the right person for you. They can also offer a payroll service if you are employing a PA and need some help with this.

For more information go to: www.independentlives.org or call 01903 219482.

**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 council and support can be either on a full-time or short breaks basis. Read more about Shared Lives in Chapter 10, or contact West Sussex County Council’s Shared Lives Scheme by calling: 01444 254463 or emailing jo.braine@westsussex.gov.uk.

**Equipment and housing adaptations**

Whether your young person still lives at home, in private rented accommodation or social housing, the Local Authority 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.
Adaptations might include providing ramp access, adding handrails, widening doors, raising electrical sockets, replacing a bath with a level access shower, or equipment for people with hearing or visual difficulties. These adaptations might be part or fully funded by the Local Authority, depending on your young person’s circumstances.

Your young person will need to be assessed by an Occupational Therapist (OT) from adult social care to see if they are eligible for adaptations. To find out more, call the Adults’ CarePoint on: 01243 642121, or email: socialcare@westsussex.gov.uk.

**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 carer is unable to look after their young person. This may be because of: health issues for the carer; the carer’s admission to hospital; 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, giving 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, the Local Authority may provide back-up services.

There’s no charge for carers of disabled children. The scheme is run in West Sussex by Chichester Careline with the support of the County Council. 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, then they can help you register with the Carers Emergency Alert Scheme, otherwise call 01243 778688 for more information, or go to www.chichestericareline.org.uk.

**Sight and hearing difficulties**

West Sussex’s Rehabilitation Officers for the Visually Impaired (ROVIs) provide specialist
information, advice, assessments and equipment to support independence for people of any age with visual or hearing impairments. They deal with referrals for people with sight or hearing difficulties, their friends or family or other professionals.

Based at the Adults’ CarePoint, you can contact them by calling 01243 642121 or emailing: asvisual.impairment@westsussex.gov.uk.

**Your needs as a carer**

Parent carers are used to having to cope and asking for help can be difficult, but your needs as a carer matter, too.

As a carer you are entitled to an assessment of your needs, even if your young person has not been assessed or is not receiving any services from the social care. You can ask for a carer’s needs assessment via the Adults’ CarePoint.

‘As parents, we feel we should cope; we push ourselves time and again. I’ve learned that at certain points I can say, “I’m sorry I can’t do this anymore.”’

**The Carer’s Assessment**

If your child regularly relies on you for care you have a legal right for a Carer’s Assessment. Adult Social Care should make you aware of this right when they carry out a Needs Assessment for your young person.

Although separate, the Carer’s Assessment can happen at the same time as the young person’s Needs Assessment. It supports carers by ensuring:

- Their work, education, training and leisure needs are considered.
- That as the carer, they have a choice about the type of caring tasks they do.
- The young person they are caring for gets the right support and services.

If your child is under 18, contact the Child Disability Team on 01403 229888, or ask your social worker (if you have one) for a Carer’s Assessment.

If your young person is over 18, contact the Adults’ Social CarePoint
call 01243 642121, or email
socialcare@westsussex.gov.uk to
ask for one.

‘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.’

• 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.
• Make sure your needs as a
carer are fully considered.
• Talk to people who have
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.

• If you need further support
and information about social
care contact Carer’s Support
West Sussex:
www.carerssupport.org.uk.
• If you need an interpreter for
this assessment, the Local
Authority should provide one.
• 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.

Other support

Discussing ideas and tips regarding
services and provision, and sharing
worries and concerns with other
parent carers can help you feel as
though you’re not alone. There
are numerous local groups for
parent carers where you can find
support – more details can be
found in the directories at the
back of the book. There are also
a number of support groups for
carers. You can find out more at
www.carerssupport.org.uk, who
also offer phone support and
counselling. Call: 0300 028 8888
for details.
'People have different thresholds. You accept your own threshold and never question whether it’s reasonable to have to do all that you do.'

**The Carer’s Wellbeing Fund**

The Carer’s Wellbeing Fund is run in partnership by Carer’s Support and West Sussex Parent Carer Forum. If your application is successful, the money could go towards things such as paying for a gym membership to help you stay fit and healthy, or you may choose to use it to do a course or have a break without the person you are caring for. More information can be found on the Carer’s Support website: www.carerssupport.org.uk, tel: 0300 028 8888. The application form is also available on West Sussex Parent Carer Forum’s website: www.wspcf.org.uk, tel: 01903 726188.

**Young carers**

Coping with a young person’s disability or additional needs can be difficult for siblings. They may have to take on household chores, or help with some care tasks and it can be emotionally draining living with people whose behaviour is challenging or whose disabilities are complex.

Under the Care Act 2014, the needs of siblings needs can be assessed, and respite for them considered. Explain your concerns to Adult Social Care and ask for a ‘Young Carer’s Assessment’.

Support for young carers can include:

- Regular breaks from caring so they can spend time with friends and enjoy the same opportunities as other children and young people of the same age.
- The chance to meet other young carers at local groups.
- Ensuring the young carer has support from other adults in their life and has someone to talk to when things are difficult.
- Supporting young carers during transition and significant life changes.

To access the service, call: 01903 270300, or email: youngcarers@westsussex.gov.uk or go to: www.westsussex.gov.uk/youngcarers.
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. 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.

Anybody who receives support from social care services can make a complaint about a service they get or one that they feel has been unfairly refused. The complaint can be raised by the young person, or by a family member such as yourself, or a friend. If your young person has the mental capacity to give their consent they must give permission for you to complain on their behalf.

You can also use the Local Authority’s complaints procedure if you are unhappy with the assessment – for example, if:

- the local authority 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.

How to complain

To make a complaint, it is best to start by speaking to your contact from the Adults’ CarePoint.

However, you can also make a complaint through their customer relations team by calling: 01243 777100 (ask for the Customer Relations Team) or emailing: feedback@westsussex.gov.uk.

You can also speak to Healthwatch about any issues you
are having. For more information and contact details, see page 157.

If you’re not happy with the outcome of your complaint, you can consider taking the matter further by raising it 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.

Local authorities must 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 Local Authority 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 791 9800.

This may all sound very daunting but don’t be put off making a complaint if you have genuine concerns, as many problems can be resolved in the early stages without having to resort to taking the more serious steps outlined above.
If your child has health needs, as part of their transition planning you’ll need to think about the switch from children’s to adult health services, to ensure they get the support they need. It is helpful if you can try to anticipate changes in your child’s health needs as they grow older and encourage them to take more responsibility for their own health, if possible.

Education Health and Care Plans (EHC Plans) include more detail about a young person’s health needs. As an EHC Plan continues until a young person is 19 years old, or 25 years in some cases, this should help with planning their transition to adult health services, as a number of things are different.

If you have had a community paediatrician from a Child Development Centre (CDC) overseeing your child’s health needs it’s important to know that once they reach 18 years of age, their care will be taken over by their GP.

Some services may also be less specialised. For example, a young person with joint problems may always have been seen on the same children’s ward, but once they reach 18 years of age they’ll need to use a general hospital ward, where the majority of other people may be elderly.

Other therapies and services may stop altogether, or not have an equivalent in adult services. For instance, your family may receive therapy from the Child and Adolescent Mental Health Service (CAMHS), but not from adult mental health services.

In this chapter we explain how health services are organised and how the transition from child to adult health services should work.
Understanding the NHS

The way many health and social care services are delivered locally and nationally has changed since the Health and Social Care Act 2012 was brought in. At a local level, the council has a stronger role in shaping services and has taken over responsibility for local health improvement.

There is now a Health and Wellbeing Board that is made up of elected representatives, as well as people from NHS Clinical Commissioning Groups, local councils, voluntary organisations and Healthwatch. This board decides the best way to improve local health and well-being. The way the money for health is spent is decided by Clinical Commissioning Groups, which give GPs and other health workers responsibility for making those decisions. And the Care Quality Commission has to make sure that services meet safety and quality requirements.

Hospital or ‘acute’ services are provided in West Sussex by a number of different trusts. You can find out which trust runs your young person’s hospital by going to: www.nhs.uk and searching under ‘services near you’. This will bring up information about the hospital, including the address, plus contact information for the relevant trust. It is worth remembering that under patient choice rules patients can choose which hospital they are referred to.

Sussex Partnership NHS Trust provides mental health, learning disability and substance misuse services for adults of all ages. Sussex Community NHS Trust provides a range of community health services including community nurses; continence services; rehabilitation, wheelchair and equipment services; and speech and language therapy.

Healthwatch is the new health watchdog intended to provide information about health services and give users a voice in how they are run. If you need advice or information about health services in West Sussex, or if you’re not happy with the service you or your
child have received, Healthwatch should be able to help. In West Sussex, Healthwatch is based in Billingshurst, but the team also runs a ‘listening tour’ which travels around the county to gather concerns, suggestions, queries and comments on health services.

If you have a query or a problem, you can call Healthwatch for support and advice. For more information, call: 0300 012 0122, email helpdesk@healthwatchwestsussex.co.uk, or visit their website: www.healthwatchwestsussex.co.uk.

If you decide to make a complaint about NHS care or treatment, Healthwatch’s Independent Complaints Advocacy Service (ICAS), can help you. You can contact them on 0300 012 0122 or email: ihcas@healthwatchwestsussex.co.uk.

Your child’s GP

As your child’s GP will be central to their health care from the age of 18 – it’s a good idea to think about whether he or she has the right GP to support them before they reach adulthood.

If you are happy that your child’s current GP is the right person to support them, it pays to build a relationship with them in advance. Make sure you talk to them early if there are things to discuss. Remember that, once your child is an adult, the GP will not be able to discuss their health with you in the way they can about a child.

If you think another GP would work better for your child, you could change to another doctor in the practice, or move to another practice altogether. The easiest way to find another GP who’s accepting new patients is through the NHS Choices website at www.nhs.uk. The website includes service reviews from other patients. If you’re not online, there should be a list of local GPs at your local library.

If a child is currently under the care of a community paediatrician, they should share information with the GP – but a parent plays an important role in helping the GP fully understand a child’s condition or learning disabilities. The truth is, after
years of going to specialist appointments, reading reports about your child, and caring for them on a daily basis, you will know their condition inside out. Be prepared to share this knowledge with your child’s GP to bring them up to speed so that you can work together to ensure your child gets the best care.

The transition to adult health services

Preparation for the transition to adult services takes place from about 13 years to ensure that you and your child are ready and understand what to expect from adult services.

For many services the switch from child to adult services happens at 18, but this can vary. It’s important to find out what happens with the specific services your child uses and to plan ahead.

GPs see people of all ages, of course, but they will start to expect young people to see them independently from 16 or 17.

Community paediatricians can see a young person until they are 19 years old. In-patient and out-patient care at hospital will usually be alongside adults from 18 years of age. For acute health care, your child may attend adult clinics from 16, although some specialist consultants may continue to see a young adult after they are 18 years of age.

Some services, like speech and language therapy, may stop seeing your child at 16 if they leave school.

The Child and Adolescent Mental Health Service (CAMHS) may see existing patients until they’re 19, although new referrals are passed to adult mental health services.

Health services are responsible for identifying whether a young person is likely to have on-going healthcare needs and to make sure these needs are met when they leave school or become an adult. They should ensure there’s a clear process for transferring responsibility and information, but parents also have a role in helping this go smoothly.
Children’s health services are free, but adults have to pay for some things like dental care and prescriptions. However, if your young person is getting benefits or on a low income, they can get free dental treatment, free prescriptions, free eyesight tests and vouchers for glasses, free wigs, boots or other appliances and transport to and from hospital.

**Prescription prepayment certificates**

If your young person has to pay for prescriptions and they are on several medications, it may be worthwhile to look at getting a prescription prepayment certificate (PPC). This allows you to have as many NHS prescriptions as you need for a set price. You can purchase a three-month certificate for £29.10, or a 12-month card for £104 (prices correct at time of going to press). If your young person needs more than three prescriptions over three months, or 11 over the course of a year, it will be cheaper to get the card. For more information go to www.nhs.uk and search for ‘prescription certificate’ or call: 0300 330 1341.

**Tips for managing the transition**

- Health services have different arrangements – wherever possible, ask staff what will happen when transition to adult services takes place. Talk to staff and other parents to get information about choices you could make now.
- There are steps you can take now that will ease the change. For example, you could arrange to visit a new clinic or ward before your child needs to attend. Some services offer a joint appointment with children’s and adults’ services just before the swap to adult services. Ask if this is an option.

**Transition planning and the health care plan**

Chapter one covered transition planning for children who have EHC Plans. Some of our children have ongoing health needs so these will need to be focused on as you consider what help they will need in adulthood so it can be written into their EHC Plan. Other children may not have any
particular health needs and you’ll just need to make sure their GP knows all about them and their needs in good time.

If your child does have ongoing health needs, health professionals are unlikely to be able to attend many, or perhaps any, of the transition planning meetings at school, but they can be asked to provide a written advice. Let the school know who’s involved in providing health services for your child, so they know who to ask. New professionals, such as a rehabilitation medicine specialist, adult neurologist or occupational therapist (OT), may need to get involved in planning for transition.

From Year 9 onwards annual reviews should planning to maintain good health in adult life. Health professionals involved in the management and care of your child should provide advice in writing and where appropriate, attend the Year 9 annual review. If your child has health needs that will continue into adulthood, the person who currently oversees their care should draft the first ‘health care plan’ following the meeting and this must fit alongside the EHC plan. They should advise on services likely to be needed and discuss arrangements for transfer to adult services with your child, the GP and you. Later, having obtained your child’s consent, they should make any referrals to adult health services and arrange the transfer of records.

If your child is also likely to have care and support needs at 18 from adult social care they should also have a transition assessment for this. This can be carried out alongside any health transition assessment. And again the EHC Plan can be used to coordinate all three.

As with all transition planning, the health care plan is not a one-off document and it should be changed and added to as your child moves through transition. It should be completed in your child’s final academic year and may need updating again just before they leave school.
Encouraging independence

As parents, we’re used to looking after our children’s health and we’re good at spotting when they’re unwell or in pain. Chapter two covered the parent’s role in helping teenage children make choices and communicate their opinions so they can become as independent as possible as adults. This applies to their health needs, too.

Some young people with complex health and social care support needs will need help to express themselves. Other young people may have such profound needs they will remain dependent on adults for on-going care. But if it’s possible, letting others know you feel ill or that something hurts is an important skill to learn. It is okay to expect more information and to have a central role in the decisions made about you and your child’s life. It’s understandable if you want to keep a close eye on the health and care services your child gets as an adult, but encouraging them to think their feelings and opinions matter and should be listened to is also part of keeping them safe in the future.

The progress towards a young person gaining as much independence as possible begins with us as parents gradually handing over responsibility to the young person. For most young people, the road to independence includes learning to look after their own health needs.

Young people communicating their health needs

Young people with disabilities, chronic illnesses or learning disabilities have to learn to communicate their health needs as much as possible.

It’s important to develop skills, relationships and confidence when speaking to health workers. An early step may be to ask health professionals to direct questions to your young person rather than addressing you.

You may need to help your child learn the right vocabulary or signs to talk about their body and health. One day they will need to be able to let other people know where it hurts or feels funny, without you to explain
for them. Make sure your son or daughter knows when to share health information. It’s important they understand the difference between a doctor asking them to talk about their health, when they need to tell them about any problems they are having, and someone asking them how they are as part of a polite conversation, when detail isn’t needed and in fact might be too much information!

‘If anyone were to ask me what message I might have for others I would tell them that they should listen to, believe and respect young people. It’s very difficult to tell anyone how you feel when they won’t listen; if you aren’t believed then you stop believing in yourself; if you’re not respected then you lose your self-respect and everyone needs self-respect.’

A word about the Mental Capacity Act and health

When a young person reaches 16, they’re legally classed as an adult in terms of decision-making about their health.

The Mental Capacity Act 2005 covers your child’s rights to make their own decisions if they have ‘mental capacity’ – including decisions about health and medical treatment. It also sets out how decisions should be made with and for them if they don’t have the capacity to decide for themselves. In these circumstances, once your young person is 16, a medical professional is likely to be the decision-maker rather than you the parent. But the decision-maker should get the views of those close to the young person unless it is a medical emergency. See page 29 for more on the Mental Capacity Act.

Bear in mind that children under the age of 16 can also be judged as being competent to make their own decisions about health care if they are seen to have the necessary maturity and understanding. For example, a GP or clinic could prescribe contraceptives in confidence to a 15 year old who asks for her parents not to be involved.
Confidentiality and medical records

The confidentiality of patients’ health information is enshrined in codes of professional conduct. Everyone has the right to have a copy of their medical records and the records should be presented in a format that patients understand. If the patient is under 18, anyone with parental responsibility can apply to see their child’s medical records, but if the GP or doctor responsible believes that your child is competent to make their own decisions about health, they should check that they consent to this. Once a young person is over 18 you’ll always need a letter giving their consent, or a ‘power of attorney’ to see them.

If for some reason you are denied access to your child’s medical records or their records have been lost, contact Healthwatch for help – see page 157.

Transferring medical records to adult services

Sometimes a young person’s medical records aren’t transferred to adult services in time for their first meeting, which means you will have to go over the young person’s medical history at the first appointment. The benefit is that you have the opportunity of a fresh start with a new service. It’s a chance to establish new relationships with professionals and put any past misunderstandings and disappointments behind you. You’ll also be able to use past experience to explain your situation and say what your child needs – or help your child to explain for themselves.

Managing medical appointments

Assessments, appointments, consultations or visits by health professionals can be stressful, worrying and tiring. It’s common for healthy, fit adults to forget a lot of what has been said and even more difficult for tired or anxious people. Bad news or painful information can come as a shock. It can feel difficult to ask the right questions to get the information you need. You may have lots of experience in
handling this, but have you also thought about teaching your young person how to cope?

‘I have found that even the most informed doctor or health person cannot provide the most basic of information if you don’t phrase the question in the right way. It’s frustrating because often you don’t know the right question to ask. The only way as I see it is to keep making it clear that you need clarity and detail. When I had to deal with the last problem which didn’t seem to have a solution, I asked the doctor what the possibilities were, and this got a much better response.’

The coping question

Sometimes, parents and young disabled or chronically sick people may say everything is fine and they’re coping, when this isn’t true.

You and your child face your challenges 24 hours a day, seven days a week. You know what the problems are and what some of the solutions may be. Tell the professional what your concerns and needs are, and help your child to do the same.

How to be prepared

Being prepared for each appointment with health professionals is important. It’s helpful to talk to your young person beforehand, when you both have a quiet moment to think at home, and write down all the things you both want to discuss. You or your child could also choose a friend to go with you to prompt you and remember what’s been said. Take a list of questions into the consultation, and note down the responses. It may take longer, but when you get home you’re more likely to have the information you need. Then you and your child can talk it over to make sure your child has understood, too.

Preparing can also be a positive opportunity to talk about issues together, as well as helping your child to practise thinking through their options.

‘There is an underlying principle that we should never assume anything. We’re always left having to assume, because we’re not informed adequately by the ‘experts’. It’s imperative to find out the facts, because, as we have all experienced, our assumptions are often incorrect.’
**Tips for appointments**

- Think ahead about the information you need from a consultation. Write questions down and involve your child as much as you can in this thinking process.
- Your child’s worries may be different from yours, so check if there’s anything they want to talk about or find out.
- Is there a leaflet or a website you can look at with your child so they can see where they are going and what equipment they may see there?
- Politeness, firmness, persistence and a good sense of humour help if the medical professional doesn’t seem to ‘get’ what you and your child need from them.

**Sexual health services**

Although it can be uncomfortable to think about your young person having a sex life, it is important to be informed and make sure that they know what sexual health services can offer. They provide:

- contraception, including long-term and emergency contraception
- access to condoms
- testing and treatment for Sexually Transmitted Infections (STIs)
- chlamydia testing for under 25s.
- pregnancy testing and counselling
- psychosexual counselling

Details of sexual health clinics and access to other services in West Sussex can be found at [www.sexualhealthwestsussex.nhs.uk](http://www.sexualhealthwestsussex.nhs.uk).

**Mental health services**

The teenage years can be an emotional rollercoaster for young people. As parents we know they’ll face the physical changes of puberty, but there are also psychological changes that will affect our children’s behaviour and emotional well-being. Many teenagers become more moody, self-centred or reckless.

Many teenagers have times when they feel anxious or low. All local secondary schools
Health and medical matters

and colleges offer counselling for young people. If your child doesn’t want to be seen seeking help at school, they can get information and advice from one of the FindItOut Centres that run across West Sussex. Go to www.westsussex.gov.uk/education-children-and-families/your-space/life/finditout-centre for more information.

For some young people, mental health issues during the teenage years may become more serious. And for a few, significant mental health needs may emerge. Persistent depression, high anxiety, serious eating disorders or really difficult or unusual behaviour are good reasons for looking for outside help.

If you’re worried about your son or daughter’s mental health, you can talk to your GP and they may refer you to Child and Adolescent Mental Health Services (CAMHS). Schools and other professionals working with your child can also refer to CAMHS. It provides help with a wide range of mental health problems for children and young people up to 18, and their families. CAMHS workers are based in the community or clinics and include a variety of practitioners including therapists and psychiatrists.

If your child is 18 and no longer at school, they may be referred to Working Age Mental Health (also known as adult mental health services) which provides mental health care for adults. Young people already getting help from CAMHS should move over to this service at 18 – or if your child doesn’t meet the criteria for adult mental health services, the CAMHS worker may suggest discharging them. Their GP would then take over their care. You can query this and ask for an assessment.

Working Age Mental Health is responsible for the provision of all mental health services for adults from 18 to 65. Services are provided through multi-disciplinary Community Mental Health Teams, day services, in-patient care, outreach team, rehabilitation services, group homes and hostels.
Doc Ready is a new website to help young people who are experiencing mental health issues to prepare for their GP appointment, and get ‘doc ready’ by building a checklist of what to talk about and learning more about confidentiality and rights. It’s designed to get a two-way discussion between the young person and GP flowing more quickly, so both parties get the most out of the limited time they have available in an appointment. Go to www.docready.org.

Annual health checks for people with learning disabilities

All adults with learning disabilities should now be invited by their GP for an annual health check, which covers physical, mental and emotional wellbeing. There is a health assessment pack for the patient to fill in with the help of a carer before the appointment. The appointment should be longer than the usual GP appointment, so there’s time to talk and not feel rushed or confused. Local GPs have been trained so they understand more about learning disabilities and how to be helpful and clear. After the health check, the GP writes up a health action plan and sends it to the patient.

Parents who have been to one of these health checks with their son or daughter have been impressed with how thorough it is and feel the GP is better placed to support them as a result. Anyone over the age of 14 who is on their GP’s learning disability register can have an annual check. It’s a great way for your young person to start their transition to adult health care.

If your son or daughter has a learning disability and has not been offered a health check by the time they reach 18, you can ask your GP for one. For more information, go to: www.nhs.uk/conditions/learning-disabilities/annual-health-checks.

Community Learning Disability Teams

There are three Community Learning Disability Teams in West Sussex. The Coastal Team is based
at Centenary House, Worthing, the Northern Team at Parkside, Horsham, and the Western Team at Durban House, Bognor.

Community Learning Disability Teams consist of staff from Sussex Partnership NHS Trust and West Sussex County Council. They include NHS staff from a variety of specialities, including: learning disability nurses; occupational therapists; psychologists; physiotherapists; psychiatrists; and speech and language therapists. They are based with social care managers and social workers from West Sussex County Council. They work closely to deliver the service in partnership.

The teams work with people aged 18 years upwards who have a diagnosed learning disability. They aim to support people with their physical and emotional health, as well as behaviours that challenge others. Referrals are taken from any source, although they prefer that referrals for eating and drinking needs come via GPs.

The intensity of support given is decided using an initial assessment of need. For families who have young people moving to adulthood, people working with them will consider how transition and other related issues may affect them. Staff may work directly with the young person, with their family, their wider network of support or sometimes indirectly.

For young people with significant challenging behaviour, there is an expert Enhanced Support Service that works across the Community Learning Disability Teams to improve outcomes.

The overall aims of the enhanced support services are as follows:

- ensuring high quality care for those who present with complex challenging behaviour
- developing capable environments and reducing placement breakdown/in-patient admissions
- ensuring people are supported safely and effectively using the least restrictive approaches
• increasing quality of life
• working with family carers and people using the service to ensure outcomes are co-produced
• creative ways of working
• disseminating and discussing local and national guidance around this specific group
• training opportunities
• sharing knowledge and best practice
• developing evidence-based care though national agendas and policy

The Enhanced Support Service also delivers the West Sussex Behaviour Support Network, a venture between West Sussex County Council, Sussex Partnership NHS Foundation Trust, service providers and families in West Sussex who support adults with learning disabilities and/or autism who present with complex challenging behaviours.

Bringing together providers, practitioners and families in this field will support this work by providing a forum where stakeholders can develop and learn. The network will meet quarterly in a central location in West Sussex, which at the time of going to press may vary. There will also be an annual focus on parent carers’ experiences.

For more information on Community Learning Disability Teams, contact:

Horsham Area – CLDT North
Telephone: 0330 222 8600
Email: ctpld.north.duty@westsussex.gov.uk

Worthing Area – CLDT Coastal
Telephone: 0330 222 7778
Email: ctpld.coastal.duty@westsussex.gov.uk

Bognor / Chichester Area – CLDT Western
Telephone: 0330 222 7888
Email: ctpld.western.duty@westsussex.gov.uk

There is also a Specialist Clinical Assessment Service, designed for people without a diagnosis of a learning disability, who may have undiagnosed autism or other
neurodevelopmental disorders. The service offers assessment, consultation and sign-posting. You can contact them by calling: 01903 846656, email: referrals.scas@sussexpartnership.nhs.uk.

**Further help on health**

Many national organisations specialise in supporting families and individuals with a particular illness or disability, including Scope, Mencap, Young Minds and Arthritis Care.

Contact ([https://contact.org.uk](https://contact.org.uk)) can provide details of the organisations relevant to your child. Some of these national groups recognise the needs of young adults are different and provide specialist information, support or training for people in transition. Try asking them what they have available for young adults.
‘I just want my son to be included in the workplace as a member of the community.’

Many of us hope that one day our young person will be able to get a job. Now young people are expected to stay in education or training until they’re 18, they can’t leave school at 16 and get a full-time job as they might have done in the past (see Raising the Participation Age, page 43), but you will still want to help them take the right steps towards employment. Some of us may not see a paid job as a realistic goal for our child but could imagine them volunteering.

This chapter provides an overview of the options available to young people, including volunteering and employment. Further information regarding employment and benefits can be obtained from www.gov.uk.

Where to look for work

If your child is ready to look for a job, a Saturday job or summer job might suit them before they leave school or college. There are many websites that list job vacancies including:

- The Argus: www.theargus.co.uk/jobs
- Gumtree at: www.gumtree.com/jobs
- Jobs at West Sussex County Council: www.westsussex.gov.uk/jobs
- West Sussex County Times: www.wscountytimes.co.uk/jobs.

Alternatively, your young person could visit their local Jobcentre Plus. In West Sussex, Jobcentre Plus are based in Bognor Regis,
Chichester, Crawley, Haywards Heath, Horsham, Littlehampton and Worthing – see the local directory at the back for more information. Jobcentre Plus helps employers fill vacancies; and provides help and benefits for people who can’t work. They also have specialist Disability Employment Advisers – read more about these below.

If your young person is looking for work, it often makes sense to approach your contacts and friends. Some of us have persuaded a local shop or business to give our child a few hours’ work experience and this has led to paid work.

But most of our children will need some extra support to be ready for and to find employment. We’ve found that it’s a good idea to talk to other parent carers and professionals to get some ideas and pick up tips about things. For example, teachers may have good advice on how to find voluntary work, get work experience or may be able to suggest other sources of help.

There is information for young people aged between 13 and 25 on Your Space, West Sussex County Council’s site for young people. It has links for work, volunteering and apprenticeships: www.westsussex.gov.uk/education-children-and-families/your-space/earn. Your young person can also get face-to-face advice at one of their FindItOut Centres: www.westsussex.gov.uk/education-children-and-families/your-space/life/finditout-centres.

West Sussex Library Service offers access to MyWorkSearch, which has links to books, magazines and online resources, as well as helping people to train, write CVs and apply for jobs in the area. For more information, go to: https://arena.westsussex.gov.uk/web/arena/learning/workskills.

Scope also has advice on how to find a job, including networking, training and where to look. For more information, go to: www.scope.org.uk/Support/Disabled-people/Work/Jobseekers/finding-jobs.
Disability Employment Advisers (DEAs)

Disability Employment Advisers or DEAs work in your local JobCentre Plus. A referral to a DEA is usually made by a Jobcentre Advisers. DEAs can provide details about government initiatives that help disabled people get work and provide referrals to suitable schemes – see the Work and Health Programme. They also provide advice on suitable job vacancies and approach the employer on the young person’s behalf if necessary and conduct an ‘Employment Assessment’ to identify the young person’s abilities and suitability for work or work-related training.

After making initial contact, the DEA will arrange an in-depth interview with the young person to establish their interests, previous work experience and education and any concerns they have about work. It can be useful for parents to attend, although it’s not always necessary.

The Work and Health Programme is a scheme that provides a full range of support to people facing significant barriers to work, including those with health conditions and disabilities. It offers assistance with personal skills, support in the workplace and help in developing a career in the longer term. There are a number of organisations working in West Sussex who can support your young person with this programme, including Pluss: www.pluss.org.uk.

Access to Work is a scheme that can provide practical and financial support to help people with disabilities into work. The programme can help to pay for:

- A communicator to help at interviews if a person is deaf or has an hearing impairment.
- A reader to help people at work who are blind or have a visual impairment.
- Special equipment or alterations to existing equipment.
- Alterations to premises or the working environment to make it accessible.
Employment and life skills

- A support worker to provide practical help at work or getting to work.
- Help towards the cost of getting to and from work if a person can’t use a car or public transport because of their disability.

For more information on Access to Work, call: 0800 121 7479, textphone: 0800 121 7579 or go to: www.gov.uk/access-to-work.

Tips to help you

- If your young person is going to places such as Jobcentre Plus, it’s a good idea to take along any paperwork that will help explain their special needs – a recent report from a doctor or educational psychologist for example.
- See it as a long-term project to help your young person show what they can do.
- Volunteering in a charity shop can help them get paid shop work and also means that they have someone to give them a reference when they leave college.
- If your young person might want to work with children, see if they can help out with an organisation such as Cubs or Brownies.

Supported internships, traineeships and apprenticeships

**Supported internships**

Supported internships are a government funded initiative that offer specialised employment-focused study programmes for young people aged 16 to 24 with learning difficulties and/or disabilities who have an EHC Plan and are ready to move into employment but need extra help to do so.

Supported Internships are run through further education colleges and the idea is that trainees will learn from expert career coaches while doing real jobs for a minimum of six months. Employers will also receive support from the coaches, to give them the skills they will need to work with disabled
young people and to help them understand the business case for employing a diverse workforce. BASE – the British Association for Supported Employment has more information about supported internships on their website: www.base-uk.org/policy/supported-internships. Locally, supported internships are offered at Plumpton College. For more information, go to: www.plumpton.ac.uk.

**Traineeships**

The new mainstream traineeships programme aims to give 16 to 24 year olds the workplace experience and job skills that employers require and are open to disabled young people with less complex needs. The aim is to get young people into work or onto an apprenticeship. The programme covers things like work research and preparation training as well as English and Maths training and a work placement.

**Apprenticeships**

As employees, apprentices earn a wage and work alongside experienced staff to gain job-specific skills. Off the job, usually on a day-release basis, apprentices receive training to work towards nationally recognised qualifications. Young people over 16 and not in full-time education can undertake an apprenticeship. They can take between one and four years to complete depending on the level of the apprenticeship, the apprentice’s ability and the industry sector. The minimum hourly rate in 2018 is £3.70 for the first year, after which apprentices receive the national minimum wage for their age group.

Employers and trainers are offered incentives to offer apprenticeships to young people with special educational needs and/or disabilities. Grants of £1,000 are available to employers and training providers and, if the business employs fewer than 50 people, they do not have to pay for the young person’s training.

To find out more about supported internships, traineeships or apprenticeships go to: www.gov.uk/apply-apprenticeship.
Employment and life skills

Alternatively, you can also find out about apprenticeships, career tasters and volunteering at: www.westsussex.gov.uk/jobs/apprenticeships, which has an interactive map.

Other initiatives in West Sussex

Network West Sussex is an initiative that is run by The Aldingbourne Trust, Circles Network, Signposts (Mid Sussex), Options LD, Outreach 3 Way, Worthing Mencap. Together these organisations offer preventive services for people in West Sussex who have learning disabilities.

My Network consists of drop-in sessions at venues across West Sussex. They offer information, advice and guidance on housing, leisure, learning, money management, health and much more. Activities and workshops have a focus on helping people to live independent lives. People must be aged over 16, but enquiries are also welcomed from family carers and friends.

My Network Plus is a housing support service for adults with learning disabilities who live independently or with family carers. Priority is given to people who are receiving support from adult social care. The service works in partnership with My Network providers to make sure individuals get the support they need to continue to live independently in their own homes.

My Network Plus is a referral only service via West Sussex County Council’s Learning Disability Teams, which each have a named link worker for the service. To access My Network Plus, people must be aged 18+ and live in West Sussex. They must have a tenancy or live with family carers and require information, advice and support to prevent their needs becoming substantial or critical.

My Network Plus customers will have their support needs met in a range of ways, with group or one-to-one support available. Typically one-to-one support will be for financial management, paperwork, developing and maintaining life-skills, monitoring health and wellbeing, emotional support, practical assistance, planning, as well as providing
links to other services and support available in the community. Every My Network Plus customer has a named keyworker who can give one-to-one advice.

The Aldingbourne Trust offers supported on the job training, life skills coaching, community learning and tailored packages to help every adult with a learning disability contribute to their community. It can also offer support to employers.

Aldingbourne Trust’s employment service, WorkAid, is designed to help local businesses, communities, people with learning disabilities and those on the autistic spectrum to maximise their potential and enjoy life together.

People supported by WorkAid have an employment consultant who works with them on an individual basis to identify the type of work they want to do and what sort of employment will suit them. Employment consultants are also trained to help those seeking work to understand the benefits system and how it will fit with the type of employment they are seeking.

WorkAid has two areas of support:

• Work Preparation: supports people who have never worked by providing individual support and training to ready them for the workplace. It covers topics such as how to search for work and apply for jobs, what is expected of an employee in the workplace, how to behave, what to wear, time-keeping and travel training. Supported work tasters and work experience opportunities are available.

• Supported Employment: for people who have some experience of work. Their employment consultant will support them to build a vocational profile identifying the environment in which they want to work, develop a professional CV outlining their experience and search for the sort of jobs they want to do. WorkAid will help individuals to identify and apply for jobs and provide support to prepare and attend interviews. When a job offer is
Employment and life skills

made, WorkAid will assist with travel-training to get to work, if needed, and support the individual once they start their job. They will also work with the new employer to help with coaching, conducting regular reviews to ensure that both the employer and the employee are happy with progress.

If an individual with a learning disability or autism already has a job and is in danger of losing it, WorkAid can support them via their Job Retention Service. As well as helping the employee, employers can contact WorkAid for advice and support to help ensure the job is successful for all concerned.

For more information, contact The Aldingbourne Trust on: 01243 546035 or email: workaid@aldingbourne.org.

A Potential Diamond is an initiative working with young people with autism or learning disabilities to maximise their employment opportunities. They look at the person’s strengths and build an understanding of what work would suit them best. Richard Lamplough, who runs A Potential Diamond, is always happy to speak to parents on the phone about how best they can guide their children on their journeys to paid employment but face-to-face support is limited to young people attending Manor Green School and Manor Green College in Crawley. It might be possible for A Potential Diamond to support young people attending Crawley College, providing funding has been approved through the college’s SENDCo.

Aspire Sussex runs adult education courses across the county, including employability skills and qualification courses for those aged 19+. It also offers a programme for adults with learning disabilities, which run within day centres as well as Aspire’s adult education centres. People with additional learning needs can be given extra support on qualification-based courses such as English and Maths. For more information, call 0345 601 0161, email: enquiries@aspiresussex.org.uk, or go to www.aspiresussex.org.uk.
Auntie Val’s Ability Centre in Storrington is a jam and chutney making community interest company that aims to get people of all ages with disabilities into work either at Auntie Val’s or within the wider business community by offering work experience, training and social integration. For more information go to: www.auntievals.com.

Blatchington Court Trust provides a service to young people under 30 who have visual impairments. They can assist with job searches, CV writing and interview practice. For more go to: www.blatchingtoncourt.org.uk and click on ‘services’, then choose ‘employment support’ from the menu.

The Butterfly Project, Horsham is a social enterprise that supports adults with learning difficulties, autism and other disabilities to engage in work and community activities so that they can develop their skills and build their confidence and self esteem. For more information go to their Facebook page: www.facebook.com/TheButterflyProjectHorsham or call: 07400 818511.

Farm Buddies connects small groups and individuals with local farms so that they can visit weekly, usually for a minimum of 12 weeks and do tasks which will be tailored to individual needs. For more, go to: www.farmbuddies.org.uk.

Ferring Country Centre is a local charity that provides training and work experience for young people with learning difficulties to help them go on to do voluntary or paid work. For more information go to www.ferringcountrycentre.org.

JubyLee Bakes CIC is a community interest company that was created by a group of young people with special needs producing ‘Special Bakes by Special People’. Their innovation was recognised in 2016 when the team won the Young Start-Up Talent Gatwick Diamond Competition, which was open to all entrepreneurs.

JubyLee Bakes is run for young people with a variety of learning disabilities, many of whom also have autistic spectrum conditions. The young people’s views and ideas are continually
incorporated into every aspect of the business. They hand make a variety of classic bakes and other treats and work to strict food hygiene standards in five-star rated kitchens. They sell their goods at markets and other events in West Sussex, as well as supplying Norwegian Airlines’ Gatwick Office, two town centre cafes, Collyer’s Sixth Form College, Mencap Trust Company tea parties and a variety of other local functions. A donation is given from most sales towards other good causes.

Young people with learning disabilities and other special needs are welcome to join JubyLee Bakes as volunteers. JubyLee Bakes can provide work-based training in baking and food hygiene. There is also the chance to develop other skills including packaging goods, and selling bakes and handling money at events.

Any young person who is interested in joining the team must have a personal assistant (PA) or carer with them who is able to actively support them during baking and sales sessions.

For more information, go to: www.jubyleebakes.org.uk, or call the general manager, Ellen, on: 01293 526509 or 07709 275278.

Impact Workability supports people with physical or sensory impairments, acquired brain injuries and carers to find training, volunteering or paid work opportunities. It also supports employers by working with them to identify their employment needs, so it can help them to recruit the right people and ensure they have the resources and understanding to support current and potential employees.

Bespoke one-to-one and group support is available in order to match people’s skills and abilities to suitable jobs, courses and training opportunities. Employment specialists work with people at a pace that is comfortable to them and seek to find solutions to the barriers that they may need to overcome. Call: 01903 730044 or email: workability@impact-initiatives.org.uk.

Southdown runs a specialist supported employment service
for people aged 16 years and over with mental health conditions to help them to find and retain paid work, undertake volunteering or to obtain life skills and qualifications. For more, go to: www.southdown.org/mental-health-recovery/our-employment-support.

Sussex Association for Spina Bifida and Hydrocephalus (SASBAH) runs a social enterprise called Saspire, which offers training and voluntary work experience to support people with physical and/or learning disabilities including those with spina bifida and/or hydrocephalus. For some people this is a direct stepping stone to employment, for those with more substantial disabilities it offers the opportunity for voluntary work, interacting with others in a safe and secure environment.

Saspire has three principal elements: training (including personal development), direct work experience, and personal support plans geared to an individual’s development needs. Volunteers commit to attend an agreed number of hours and days each week to enable their needs to be met.

In West Sussex, Saspire operates from SASBAH’s Worthing premises. It comprises a large workspace and office, with fully accessible facilities. For more information, please contact the SASBAH office on: 01825 873045, or email: office@sasbah.org.uk.

West Sussex County Council also runs career taster schemes for the following: undergraduate placements, graduate internships, work placements apprenticeships and voluntary work. They are particularly interested in helping people who may face barriers to employment due to their age or health conditions and those who are long-term unemployed. You can find out more at: www.westsussex.gov.uk/careertasters.

Voluntary work

‘By doing voluntary work it gets me out of the house and gives me more confidence at being independent and doing stuff on my own.’ (Simon, 23)
Unpaid voluntary work can be a stepping stone into work. Young people can work voluntarily without it affecting their benefits and, even if it doesn’t lead to a job, it’s a way of meeting new people, gaining new skills and getting experience of the working world.

Some parents find volunteering opportunities for their young people through their own network of friends and family. Think creatively about where their strengths and interests lie – it’s always worth asking around in your social circle as you never know what might work out.

‘Joe loves trains and transport. We found he could volunteer to look after the flower planters on some station platforms in the area and this means he gets to travel between them by train with his support worker.’

Young people can gain volunteering experience through the Duke of Edinburgh Award. It offers all young people aged between 14 and 25 the opportunity to help others, acquire new skills, experience adventure and make new friends, while at the same time working towards a nationally recognised award. Young people with SEND are welcome but some centres have specialist knowledge and experience in delivering DofE for young people with additional needs, so if you have questions about accessibility or meeting your young person’s needs email: dofe@westsussex.gov.uk (local) or find out more at: www.dofe.org (national).

There are also volunteering opportunities available with West Sussex County Council. To find out more, go to: www.westsussex.gov.uk/volunteering.

The National Citizenship Service is open to all 16 and 17 year olds – young people with SEND are eligible up to 25 years of age. The aim is to help young people build their skills for work and life, take on new challenges and meet new friends. It runs in the spring, summer and autumn. It includes a short time away from home as well as a team project to help the local community. To register ring 0800 197 8010 or register on their website: www.ncsyes.co.uk.
Skills development

M8s is run by the youth interventions team in Bognor and Horsham. They offer a person-centred skills development programme, which focuses on the young person’s needs and developing skills for life and supporting them to work towards a Youth Achievement Award.

Once they have achieved their goal, the young person will then be supported to move on to other opportunities in their area to socialise and develop their skills. For more information, contact Maria Parton on 0330 222 3166 or email: maria.parton@westsussex.gov.uk (Bognor) or Gail Walker on 0330 222 3109, email: gail.walker@westsussex.gov.uk.

Self-advocacy

Attending a self-advocacy group can be a way for young people with SEND to make their voices heard and to develop their confidence. Both are key life skills and will help your child to maximise their independence.

There are a number of self-advocacy groups running in West Sussex, including:

Asperger’s Voice Self-Advocacy Group is a community group run by and for adults with Asperger’s. Call: 07471 353062, email: aspergersvoice@gmail.com or go to their Facebook page: www.facebook.com/AspergersVoice.

Asperger’s Syndrome Self-Advocacy (ASSA) is an independent self-advocacy group in Littlehampton for adults with Asperger’s. The group meets on the second Wednesday of the month and is supported by staff from Impact Initiatives. For more information, call: 07471 353062 or email: assagroupws@gmail.com.

People Come First is an independent self-advocacy group in Horsham for adults with learning disabilities, run by adults with learning disabilities. The group meets on the second Tuesday of the month and is supported by staff from Impact Initiatives. Call: 07920 234605 or email: pcffhorsham@gmail.com.
SpeakAbout is an independent self-advocacy group in Worthing for adults with learning disabilities. The group meets on the fourth Thursday of the month and is supported by staff from Impact Initiatives. Call: 07741 241209 or email: worthingspeakabout@gmail.com.

Speak Up is an independent self-advocacy group in Burgess Hill for adults with learning disabilities. The group meets on the third Monday of the month and is supported by staff from Impact Initiatives. Call: 07776 072603 or email: midsussexspeakup@gmail.com

Voice is an independent self-advocacy group in Bognor Regis for adults with learning disabilities. The group meets on the first Thursday of the month and is supported by staff from Impact Initiatives. Holds a coffee shop drop-in twice a month. Call: 07748 088427 or email: jo.delaney@impact-initiatives.org.uk.
'He’s always done lots of things out of home and at college and he’s watched all his brothers and sisters leave and he wanted to leave home. I suppose it’s a natural thing...’

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

This chapter covers what housing options are available for young disabled people in West Sussex. The experiences of parents and young people who have already made the move show that it’s important to think and start planning early for this major move. After all, having the right living space in the right location with the right people is extremely important to a person’s happiness and well-being.

You can start discussing housing options when your child is still at school as part of their transition planning annual review meetings.

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

**Where do people live?**

Housing arrangements for disabled people have come a long way since the 1960s, when people were housed in institutions that kept them apart from the rest of society. Disabled people spent
many years lobbying to have the right to live in the community like everyone else. This, plus changes in attitudes and government policy have enabled thousands of people to move out of long stay hospitals, campuses and residential care. But according to a Mencap report, ‘Housing for people with a learning disability’, there’s still some way to go to ensure everyone has free choice in their living arrangements and access to support that entirely meets their needs.

You can find advice on housing and supported living at what was Housing and Support (now called Learning Disability England). It has detailed information and resources around housing options, rights and the law, good practice and policy at: www.housingandsupport.org.uk. You can find out more about Learning Disability England at: www.learningdisabilityengland.org.uk.

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

Housing in West Sussex

In West Sussex, only 12.8 per cent of households live in council housing or housing association properties. Average house prices are high, which means affordable housing is hard to come by. There are several different types of accommodation options for people with a disability. They might choose to live with their family; in private or social rented housing; in owned accommodation; in residential care or specialist placements; or in adult placement schemes called ‘Shared Lives’.

The growing number of disabled people means that more people will need the Local Authority to make housing arrangements for them so they can live as independently as possible.

‘So eventually, Clare said that she had found somewhere that would be suitable, but he would have to live with three others because they weren’t going to fund for one or two, it had to be four. You know that autistic children have huge problems with relationships and friendships.’
But Tommy [and] one of his classmates ... seemed to have a link to each other. They seemed to communicate in their own language and have affection for one another. So they are living together and the other two came in a bit later.’

Planning for the future

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

Because disabled young people are likely to depend on formal and informal support, planning for the future is crucial.

Generally speaking, disabled young people, their families and local authorities should take part in detailed planning and assessments before any change is made to living arrangements. This is to make sure that the new accommodation meets the needs of the young person. Planning is also a way of involving your young person in decisions about where they want to live and who they want to live with.

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

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

As we explained in Chapter 7, once your child is 18 years old, the social care support they need is provided through adult social care. Adult social care workers carry out needs 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 young person. In West Sussex enquiries are initially directed through the Adults’ CarePoint on: 01243 642121, or email: socialcare@westsussex.gov.uk.
Each of the district/borough councils in West Sussex have their own Housing Options Officers with whom you will be able to discuss your young person’s situation. You will be offered advice on what you could do yourselves or assistance to move into suitable housing. Note this service is only available to people who are over 16.

**How the council commissions (buys) services**

West Sussex’s housing and social care providers have been ‘approved’ through an accreditation process. They are also monitored by the council’s contracts team. Commissioners (people whose job it is to buy these services) work with providers to ensure the services are appropriate and value for money.

**Types of housing for young people**

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

The typical experience for young people is to live with their families until some time in their late teens or early twenties, when they begin the journey to independent living. They may move into shared flats or student accommodation before moving on to living alone, with friends or partners. However, the same is not always true for young people with disabilities and other support needs.

Official statistics show that the majority of adults with learning disabilities live with their families or in residential care. Councils are keen to support the young person to stay living in their family home, for as long as the family are able to sustain this and meet the young person’s needs. They can offer help to make this work. Some support can be provided through ‘outreach’ support, day activities, short breaks/respite or access to social clubs. This includes services specialising in working with young people, autism, complex health needs and other needs.

WSCC Adult and Children’s services can organise short breaks for adults with more complex needs. But be warned that this
provision is for all ages so your young person may not always be with people their own age.

If your young person has a Personal Budget, it can be used to employ Personal Assistants (PAs) or to meet their needs in other ways. We’d suggest that it’s really important to think about what’s best for your son or daughter in the long-term – don’t wait until there is a crisis when they may have to move out of the family home.

Support at home costs around £15.00 per hour but provider prices vary. The money to pay for this can come from the package of support agreed by adult social care and can be arranged by the council or managed by the young person or their family as a Direct Payment. For more about Direct Payments, see page 143.

**Supported Living or Housing**

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

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

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

In supported living or housing the young person can have a tenancy agreement, which gives them more housing rights. They can claim housing benefit and keep most of their benefits such as Personal Independence Payment (PIP).

Supported housing focuses on helping the young person to develop their life skills and independence, as well as learning to share the responsibility for
cooking, cleaning and shopping. The positive side of this form of accommodation is that the young person will have company as well as the security of a service and staff team. However, like all young people, it’s important to remember they can be friends one moment and fall out the next and staff may leave, which can be disruptive.

‘Well they are teenagers and they do get up to trouble sometimes and they have arguments as well. I’ve had quite a few times when I have worried... but staff have said don’t worry; they are friends but they do have ups and downs.’

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

Who can use supported living schemes?

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

Choosing the right supported living scheme

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

Supported living is provided by a range of providers in West Sussex. Despite this choice, it can still be difficult finding the right place for your young person when they need it. Once again, good early planning is the key to identifying the right service for your child.

Details of supported living accommodation in West Sussex and further afield can be found on the Care Choices website at www.carechoices.co.uk. You just put in your postcode and the type of care you are looking for and you can browse the results.

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

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

Where can I find out more?

The following list is a selection of organisations that have further information about supported living schemes, or run their own schemes.

- **Aldingbourne Trust** – offers supported living, living in the community and transitional support to help people develop the skills they need to live on their own. For more, go to www.aldingbournetrust.co.uk/care-and-support/housing.

- **Chailey Heritage Foundation’s Futures Accommodation** is for young adults aged up to 25 with complex needs and offers a stepping stone to young people moving into adult life. For more information, go to: www.chf.org.uk/futures-accommodation.html.

- **Grace Eyre** offers information and support to people with learning disabilities, including supporting people to find a suitable home as well as a supported living scheme. For more information go to: www.grace-eyre.org.

- **Mencap** has detailed information and advice on supported living. See: www.mencap.org.uk/advice-and-support/housing.

- **Outreach 3 Way** offers people with learning disabilities or autism supported living services. For more, go to: www.dimensions-uk.org/about/outreach-3-way.

- **Scope** has a guide to living independently, which you can access at: www.scope.org.uk/support/disabled-people/independent-living-guide.

- **South Down** provides supported living for people across West Sussex who have a range of disabilities: www.southdown.org.learning-disability-support.

- **West Sussex Connect to Support** has a searchable database of organisations that
offer a variety of residential options. Go to: www.
westsussexconnecttosupport.org and click on ‘Services’ to search.

Shared Lives

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

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

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

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

Who can use Shared Lives services?

To access Shared Lives, a young person needs to be assessed by Adult social care to see whether they are eligible for this scheme, so if your child has a social worker, talk to them about this option.

‘I have a lot less responsibility, which is actually one of the best things... so the involvement that I do have with Becky is on a more personal level, just me and Becky, rather than dealing with all the bureaucracy and the form-filling and phone calls and meetings and all of that. I don’t miss that.’

A financial assessment will be carried out by the Local Authority in order to see if the person needs to make a financial contribution. To find out more, go to: www.westsussex.gov.uk/sharedlives
'The best thing for me is that Becky is happy where she is. If Becky was living independently, but she was unhappy, I would find that very difficult. But because it’s what she wants, it’s what she decided and it’s going well, that’s the best thing.'

Residential care

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

Residential care almost always involves living with other disabled people who have been placed there. So there is less choice of the people the young person will live with or the people who will support them. In the past, this was often the only housing option for people with learning disabilities who, for whatever reason, could no longer live in their family home. For this reason, many of these homes tend to cater for older people rather than young people.

The exceptions to this are some residential care homes for younger people with complex physical/health needs or those with complex or challenging behaviours.

Residential care homes vary in size from three or four to ten or 12 rooms in a house. Most are ordinary homes on ordinary streets. You have to find the right vacancy, and compatibility with other residents can be an issue.

In a residential home the young person will not have a tenancy, they will have a licence, which means they have fewer rights. It also means that the landlord can has access to their room and can change their room.

Who can get residential care?

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

**Choosing residential care**

You can find details of local care homes in West Sussex and further afield on the Care Choices website at www.carechoices.co.uk.

Care homes have to be registered, so are subject to inspection by the Care Quality Commission (CQC). You can see details and recent inspection reports of care homes on the above website or on the Care Quality Commission’s website www.cqc.org.uk.

**Social housing**

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

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

Unfortunately, there is high demand for social housing in West Sussex and it can sometimes take a long time bidding before there is an offer of a property. Also remember that all of the young person’s support needs will need to be arranged before they move in.

In some areas of West Sussex, to register for social housing you will need to speak to your district council, most of whom have application forms online. Eligibility rules for each housing register vary. You can find contact details for your district or borough council in the directories, on page 218. Alternatively, go to www.westsussex.gov.uk and search for ‘affordable rented housing’.
If you are located in Adur and Worthing, Chichester, or Mid Sussex, to apply for social housing locally you need to register with the choice-based letting scheme Sussex Homemove. You can download an application form from the council’s website. Go to www.westsussex.gov.uk and look under Housing, or go to www.homemove.org.uk.

You can also visit any of the local housing offices where staff can help you with form-filling or any queries you may have. You may need to complete a medical self-assessment form for your young person with information about any disabilities, impairments, medical conditions or mental health needs they may have.

For young people with mobility needs, there is a separate mobility self-assessment form. Ask the young person’s GP or any other medical workers for supporting information. If the young person has a social worker, you could ask them for a supporting letter.

A word about accessible housing

West Sussex County Council has a register of all their adapted and wheelchair accessible homes. All those applying for the accessible housing register are assessed for mobility needs and coded 1, 2, 3 depending on the severity of the need. All properties available to let are then advertised as being suitable for particular codes with the priority going to that group. You can also look for accessible housing on the Accessible Property Register: www.accessible-property.org.uk.

Home ownership schemes

HOLD – Home Ownership for People with Long-term Disabilities is a Government-backed scheme that helps disabled people to buy a shared ownership home and live independently by buying an initial share in the house that they can afford. If none of the shared ownership homes available can meet the person’s needs, the disabled person may qualify to buy a home on the open market.
A place to live

More information is available at: www.helptobuyese.org.uk/help-to-buy/hold or call 03333 214044.

The private rental sector

This means renting a property owned by a private landlord. For some people, it can be a good option for finding somewhere to live as it can be difficult to get social housing (owned by the council or housing associations) in West Sussex.

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

Tenancies

Private sector landlords normally give their tenants a six or twelve month fixed term Assured Shorthold Tenancy to begin with. After the fixed term is up, the landlord may decide to give another fixed term tenancy, or decide not to but allow the tenancy to continue on what is called a statutory periodic tenancy or may decide to end the tenancy. If the landlord doesn’t want to extend the tenancy they must usually give two months’ notice and may have to seek possession through the courts. The landlord is responsible for most repairs and maintenance.

Housing benefit in private accommodation

Rents are higher in the private sector than in social housing. Some rents may be higher than the amount that housing benefit will cover. Some private landlords will not take tenants who are on housing benefit. Contact the housing benefit department to work out how much housing benefit the young person may be able to get.

Moving in costs

You usually need one month’s deposit and one month’s rent in
advance before you can move in and if you go through an agency you may also have to pay agency fees. Remember, if your young person needs support to live independently you will need to arrange this before they move in.

At the start of the tenancy, when your young person has paid any fees and the initial deposit, the landlord must protect the tenancy deposit in a government approved scheme. The deposit should be returned at the end of the tenancy, although the landlord can make reasonable deductions from the tenancy deposit if the tenant has caused damage or hasn’t paid the rent. You can find out more about tenancies and your young person’s rights as a private tenant at https://england.shelter.org.uk.

Getting adaptations to housing

The council can help adapt a property whether you own it, rent privately, or are a council or housing association tenant.

This can include providing equipment to make daily tasks easier, adapting your home to improve access or help with bathing facilities. Adaptations might include providing ramped access, adding handrails, widening doors, raising electrical sockets, replacing a bath with a level access shower or installing special equipment for people with hearing or visual difficulties.

These adaptations may be funded or part-funded by the council depending on your circumstances through a Disabled Facilities Grant. For further information contact the Adults’ CarePoint on 01243 642121, or email: socialcare@westsussex.gov.uk and ask for an assessment, which will be done by an Occupational Therapist.

Tips on choosing somewhere appropriate

‘If everyone is quietly in their rooms I would be uncomfortable. I would look for staff that are really understanding and who join in with them.’
• Listen to what your young person wants.
• Be assertive with social services – if you’re not happy with what’s been offered, push for alternatives.
• When you visit a possible placement, make sure people look relaxed and happy with the staff.
• Try and find a nice short break placement first that you feel happy with, be it one or two nights a week, so your child can get used to it. If a placement is available you may be able to build up the amount of time your young person spends there.
• It’s important to have good communication with all the people who are looking after your young person.
• Give the carers as much information as you can, including your routines.
• Build a relationship with the carer and be accepting of the fact that they may do things differently.
• Accept that having less responsibility also means that you have less influence.

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

‘They are all learning because they don’t know that person at all. So what I did was I got myself some cards and I put: these are the foods he likes; these are the activities that he likes. I put different things on different cards and gave them to the carers to give them some guidelines. And also what might upset him, anything to do with that.’

‘Support [your young person] by helping them do washing up and washing their clothes and putting clothes in the washing machine and helping them put the machine on ... Teach them to do it and then they can do it the next time.’ (Becky, 18)
Travelling independently is an important part of growing up, but for some young people this will always be difficult without support. This chapter looks at ways of making travel easier and includes information about special allowances and concessions available to disabled young people.

**Travelling to college**

**Help for all young people**

Students aged 16 to 19 years who are in full-time further education can get a third off their rail travel to and from college with a Sussex Student Card.

The discount is available to full-time students aged 16-19 whose home address is in West Sussex, Brighton and Hove, or East Sussex. It applies to most local train journeys (not to London) and season tickets of between one month and one year. To get the discount you need to have a Sussex Student Card – local railway stations, schools and colleges have application forms for this. For more information and to download the application form go to: www.westsussex.gov.uk/studentcard.

Once you have the card, you can apply for a season ticket at: www.southernrailway.com/tickets/discounts-and-railcards/further-education-season-tickets.

National Rail also provides a Young Person’s Railcard for 16 to 25 year olds, which entitles the cardholder to a third off rail fares. It costs £30 a year or £70 for three years. Under the same scheme, mature students can also apply for an annual railcard, as long as they can provide evidence that they are in full-time education. For more information, call 0345 3000 250, email: railcardhelp@railcards-online.co.uk or visit www.16-25railcard.co.uk.
Compass Travel offers 25 per cent off adult bus fares to students aged 16 to 19 who are in full-time education: www.compass-travel.co.uk/concessionary-fares.

Metrobus offers 25 per cent off adult fares for students over 16 in full-time education. To get the discount, students must register for a free Student key card, which can then be topped up online or at the Metrobus travel shop in Crawley. See: www.metrobus.co.uk/student-eligibility-and-id.

National Express offers a third off fares to full-time students aged 16 to 26 years through its Young Person’s Coach Card scheme. See: www.nationalexpress.com/en/offers/coachcards/young-person. They also offer a separate discount scheme for people with disabilities, see page 206.

Stagecoach offers discounted Termrider and Unirider tickets for school and college students, plus a weekly student rate, called Megarider Gold. See: www.stagecoachbus.com/tickets/unirider.

Unizone is a season ticket scheme giving unlimited travel to college and university students within specific Unizone areas. It is open to students studying at any of the universities in Sussex, as well as Plumpton College, and young people at college who have a valid NUS card. For more details go to www.southernrailway.com and click on ‘Tickets and fares’.

Help related to disability or SEN

If you think your child will need support getting to and from college, flag it up with the Senior Planning Coordinator and during their annual review at school.

West Sussex County Council has a transport policy statement for students in further education, which is available on their website. Transport may be available if your young person meets their eligibility criteria.
Parents will be asked to make a contribution towards transport costs unless the family is on a low income. For more information visit www.westsussex.gov.uk/schooltransport and click on ‘Post-16 and college transport for students with SEND’.

Schools and colleges also have a 16-19 Bursary Fund for students from low income families who may not meet the eligibility criteria for help with transport.

**Independent travel training**

‘She looks like any other teenager... but she’s leaving school with a reading age of less than nine years. She still can’t do independent travel on the bus, we have to practise journeys.’

Some schools and colleges offer independent travel training to help young people to get about on their own. Parents may worry about a child’s vulnerability, but there are many advantages in the long run if your child can learn to travel independently – including opportunities to participate in social and leisure activities, training, further education and employment. It may also free up your time if you don’t have to be your child’s chaperone or taxi service.

Ask your child’s school or college about travel training, what it will involve and how you can support your child to learn these life skills. Giving this a try should not mean your child’s existing transport arrangements will be cancelled.

‘My son’s self-confidence and self-esteem have blossomed. In his eyes, the world has become accessible and he feels that he fits in with his peers, which is so important to a teenager.’

Some short breaks or 1:1 buddying schemes offer trips out in the community for young people. As part of this, there may be the opportunity for young people to travel on public transport, which can be a good time to practice journey planning and build independence.

**Using technology to help**

If your young person has a mobile phone, these can be used to encourage independence and also to provide parent carers with reassurance.
Of course, the easiest way to do this is for your young person to check in with a text every now and then – to let you know when they leave and arrive somewhere. However, if you feel you want more reassurance, a number of location apps are available – these offer the option for tracking in real time and may be of particular benefit during the first few journeys your young person makes independently. For example:

**Life360 Family** is a free app available for iPhone and Android that allows you to choose two locations, such as ‘home’ and ‘school’. When your child sets off for school, the app checks them in and sends you a text to let you know they’ve arrived safely. There is also a ‘panic’ option, which sends texts and emails to carers showing your child’s precise location. The paid option allows you to choose additional locations.

**Footprints** is another tracking app, with the added benefit of ‘geofences’. This allows you to set boundaries in which your child can move freely, but if they cross the geofence, a notification will go to your phone to let you know. This could be useful to allow parent carers to gradually expand the area for independent travel.

There is also an array of wearable tech to suit all ages and abilities including smart watches with in-built GPS trackers, some of which can also receive calls from and make calls to pre-programmed numbers.

There are pocket trackers, which can be slipped in a bag or jacket. Some have in-built panic buttons which can be programmed to call your mobile phone. There are also GPS trackers which can be clipped to clothing or slipped in shoes.

**Journey planning**

Teaching young people to plan their journeys is an important part of travel training, and there are lots of local and national resources that can help.
West Sussex County Council has a dedicated cycle route planner, which is available as a free app for most smart phones. You can visit www.westsussex.gov.uk/cycling for further information.

For both national and local travel information on journeys by bus, coach, train, foot or bike, plus useful contact details and links to help you plan your route you can also check: www.westsussex.cdmf.info.

To plan journeys and to compare travel options, you can also go to www.traveline.info.

If you’re planning to travel in and around London, Transport for London (TfL) has a journey planner on its website at www.tfl.gov.uk as well as information on assisted travel, which includes some useful ‘how to’ videos.

For local and national rail travel, contact National Rail Enquiries or visit their website at www.nationalrail.co.uk or call 03457 48 49 50. National Rail Enquiries provides travel information for disabled passengers and people with reduced mobility. National rail also has an app for Windows, Apple and Android phones.

For coach journeys, National Express has an Assisted Travel service. Call: 0871 781 8181. It also has an app for smartphones.

Online resources like Google maps or sites like www.streetmap.co.uk allow you to plan journeys from one point to another and provide you with text and map details you can print out. Your young person may also benefit from downloading one of the many travel apps that are available for smart phones. Many provide live travel information, which can be really helpful when services are cancelled or delayed.

Locally, the Aldingbourne Trust can help disabled people to plan travel, apply for discount schemes and book tickets. Go to www.aldingbournetrust.co.uk/care-and-support/advice-guidance and click the ‘travel’ tab to find out more.
Bus travel

Local bus travel

More information for each of the local bus companies operating in West Sussex can be found at: www.westsussex.gov.uk/buses, go to ‘Bus operators and fares’. This also includes contact information for each company.

Disabled person’s bus pass

Anyone aged five or over with a ‘physical or mental impairment’ may be eligible for a Disabled Person’s bus pass, which offers free bus travel 24/7 for West Sussex residents whose journeys start or finish in the county. There may be time restrictions if the pass is used in other areas. Young people who are permanent residents of West Sussex will be eligible if:

- They have a disability or have suffered an injury, which has a substantial and long-term adverse effect on their ability to walk.
- They do not have arms, or have long-term loss of the use of both arms.
- They are blind or partially-sighted.
- They are profoundly or severely deaf.
- They are without speech.
- They have a learning disability.
- They applied for a driving licence they would have it refused on the grounds of a medical condition.

Passes are issued by West Sussex County Council. For more information and an application form go to their website www.westsussex.gov.uk and search for ‘Free Disabled Person’s Bus Pass’. Alternatively you can call 0330 222 6222 or email buspass@westsussex.gov.uk.

If young people do not wish to have the bus pass, WSCC offers a free Disabled Person’s Railcard, see the section on train travel for more information.

If your young person lives in Mid-Sussex, is over 18 and eligible for the bus pass but unable to use it because of their disability, they may be eligible for taxi vouchers. See the section below on taxi travel.
Helping Hand Scheme

This is a card scheme, which is being supported by several bus companies in West Sussex including: Big Lemon; Compass Travel; Metro bus; Southdown PSV; Stagecoach; as well as Brighton and Hove Buses in East Sussex. It is a simple card that the holder can hand to the driver to give them extra information such as ‘Can you call out the correct stop’ or ‘Needs priority seating’. It does not disclose the person’s condition to the driver, but this can be added to a ‘bespoke’ card, if preferred. To apply go to: www.metrobus.co.uk/helping-hand-scheme, or go to www.westsussex.gov.uk and search for ‘Helping Hand scheme’. Alternatively, you can find out more by calling 01273 886200.

National Express Disabled Coachcard

This card offers a third off travel on National Express coaches throughout the UK. There is a charge for the card and it is valid for a year. For more information go to www.nationalexpress.com/en/offers/coachcards or call their contact centre on 0871 781 8181. If your young person is a wheelchair user, they recommend that you book assistance at least 36 hours before you travel by calling 0371 781 8181.

Community Transport

There are various Community Transport Service providers operating across West Sussex that can help people who find it difficult to use public transport. They run regular services for people to go shopping. Some buses have a passenger lift or a low-level floor, so they’re ideal for people who can’t manage steps or who use a wheelchair. Drivers are trained to help passengers on or off the bus and to make sure the journey is smooth and comfortable. You can find out more about the services on offer in your area by going to www.westsussex.gov.uk/communitytransport.

Compass Card Offers

If your young person has a Compass Card, see page 90
for details, it’s worth checking the Compass website for travel discounts. A number are available, including Brighton and Hove bus company, which offers discounts for Compass card holders over 18 who are not in full-time education and Big Lemon, which offers discounts on a number of Brighton & Hove routes for West Sussex Compass Card holders. For more, go to: www.compasscard.org.uk.

**National Train travel**

The National Rail Enquiries website at www.nationalrail.co.uk provides information for disabled passengers about accessibility, train operating companies and the Disabled Person’s Railcard, as well as accessibility maps that show which stations have lift access to platforms and information on staffing levels. You can telephone National Rail Enquiries on: 03457 484950.

Your young person may qualify for the Disabled Person’s Railcard if they have a disability that makes travelling by train difficult. The card offers the young person and an adult companion a third off most fares across the UK. For more information, contact the Disabled Person’s Railcard office on 0345 605 0525, email disability@raildeliverygroup.com, or download an application form at www.disabledpersons-railcard.co.uk.

The Disabled Person’s Railcard can also be set on an Oyster card, so that a young person gets a third off fares on the London Underground. Holders can also get a third off an Off-Peak Travelcard for one adult travelling with them.

There is usually a charge for a Disabled Person’s Railcard. However, if a young person does not wish to apply for the Disabled Person’s Bus Pass, see page 205, West Sussex County Council offers a free one year railcard instead.

Southern Rail also offers a free Travel Support Card, designed to help anyone who finds it tricky to ask for help when travelling. The card can include details about your journey, what you might need help with and who to contact in an emergency.
To find out more, go to: www.southernrailway.com/travel-information/travel-help/assisted-travel/support-Whilst-travelling.

Access and assistance with rail travel

If you’re travelling by train you can book special assistance so that rail staff will help you during your journey. The train company can organise for someone to:

• meet you at the entrance or meeting point and accompany you to your train
• provide a ramp on and off your train if you need one
• meet you from your train and take you to your next train or the exit
• carry your bag

You can book help at short notice – although some companies ask for up to 24 hours’ notice – by calling: 0800 022 3720, or by filling in the online form at: www.disabledpersons-railcard.co.uk/using-your-railcard/passenger-assist. You can also book in person at any staffed train station.

Taxi travel

Taxi companies provide wheelchair-accessible cabs, but there are a limited number of cabs available, so you may have to wait longer. It’s best to book them in advance.

In Mid Sussex, if a young person is over 18 and qualifies for a Disabled Person’s Bus Pass but cannot use buses because of their needs, they may be eligible for taxi vouchers instead of the pass.

To find out more, go to www.midsussex.gov.uk/travel and click on ‘Taxi Vouchers’, call 01444 477450 or email taxivouchers@midsussex.gov.uk.

Car travel

Free vehicle tax

Young people are exempt from paying vehicle tax if they:

• Receive the higher rate mobility component of DLA or the enhanced rate mobility component of Personal Independence Payment (PIP).
• Have a car that is only used by them or for them. The car could be owned either by the young person, or by their parent or carer. The vehicle must be registered in the disabled person’s name, or their nominated driver’s name (this may be you as their parent carer). The vehicle must only be used for the disabled young person’s needs. It cannot be used by the nominated driver for their own personal use.

• To apply, you must get a Certificate of Entitlement to show that your young person receives PIP or DLA. Call: 0800 121 4433 (PIP) or 0800 121 4600 (DLA). You can then take the certificate to your local Post Office, along with the vehicle’s V5 and a valid MOT certificate. For more information go to: www.gov.uk/government/publications/ins216-how-to-apply-for-free-disabled-tax.

Blue Badge scheme

If your young person gets the higher rate mobility component of DLA, or eight points or more under the ‘moving around’ section of the mobility component of PIP, they will be entitled to a ‘Blue Badge’. A person who is severely sight-impaired will also meet the required criteria. It is possible to get a Blue Badge if you don’t claim DLA/PIP but ‘have a permanent and substantial disability which means you are unable to walk; or you have very considerable difficulty in walking.’ In this case a young person may need to attend a mobility assessment clinic. There is a fee for issuing the badge. A booklet is issued with every Blue Badge to explain how to use it properly.

If a young person has a Blue Badge, they or the person driving them need to stick to the rules about its use. For example, if they display the badge the wrong way round, or with the expiry date hidden, they can get a parking ticket. In West Sussex the scheme is administered by the County Council. Call: 01243 777653 or apply online at: www.westsussex.gov.uk/bluebadge.
Motability

Motability is a scheme which means some of the money from the mobility component of Disability Living Allowance (DLA) or Personal Independence Payment (PIP) can be used to lease a car. If your child receives the higher rate mobility component of DLA or the enhanced rate of mobility for Personal Independence Payment (PIP) and it has at least a year to run, you or the young person (if they are 16 and over) can use the mobility part of the allowance to lease a car, scooter or powered wheelchair.

Motability may be able to offer extra support to drivers aged 16 to 24 (whether the young person or a named driver) through Pass Plus. This is a free six-hour course provided by the AA, specifically designed to help young drivers to drive more safely. Successfully completing the course in addition to passing the driving test can reduce the insurance excess for young drivers. Contact Motability to find out more.

Some disabled people have found that, under PIP’s tougher rules for assessing problems with walking, although they were eligible for Motability under DLA they are not when they are reassessed for PIP. If this happens, the person’s Motability vehicle has to be returned. To help people in this situation, Motability are giving support and advice in the form of a ‘transitional support package’. There is more information on their website at www.motability.co.uk or you can call 0300 456 4566.

Learning to drive

Young people can begin to learn to drive at 17, unless they receive the higher mobility component of DLA or the standard or enhanced mobility component of PIP, in which case they can start learning when they are 16.

Learning to drive is expensive. The Family Fund offers a grant to help eligible young people aged 16 and 17 take the first steps in learning how to drive. Their Driving Ambitions grant supports the young person to get started
by funding a combination of: a provisional licence; theory test; learning materials, such as books or DVDs; and a first taster lesson. This is only available for an eligible young person who has not yet had any driving lessons. For more information call 01904 550055 or go to www.familyfund.org.uk.

The Family Fund cannot provide support for ongoing driving lessons. If your young person is aged between 16 and 24 and a Motability customer already, Motability may be able to help with the cost of driving lessons. Contact their Grants team to discuss this.

There are several Independent Mobility Centres around the country that provide advice about learning to drive. The nearest centres locally are in Worthing, Leatherhead and Carshalton. Staff can give advice and provide assessments to determine the support needed to help a person to drive. The centre also has a list of driving instructors who teach using specially adapted cars, or have experience of teaching people with disabilities. They can also provide information and advice on getting a car adapted for a young person’s needs. For more information, go to: www.drivingmobility.org.uk.

A number of organisations offer driving experiences for under 17s. Admiral’s Young Driver scheme offers half-hour lessons for children aged five to 17, which can be a great introduction to driving in a safe environment. They are fully inclusive and experienced at teaching young people with disabilities and also offer lessons in adapted cars with hand controls for wheelchair users. For more, go to: www.youngdriver.eu.

**The Theory Test**

The driving test is made up of a theory and a practical section. Theory tests are usually held at test centres, which are generally wheelchair accessible and offer specialist facilities for disabled people. If your local centre isn’t accessible to your child, they can take the test at home or at a different centre.
There are special arrangements for people who have difficulties with written language or working with computers when taking the theory test. It usually takes around 40 minutes to complete the written test, but disabled people can apply for additional time by completing the ‘special needs’ section on the application form.

The Practical Test

No matter how serious a young person’s disability might be, they will take the same driving test as everyone else. When booking the practical test, young people should let the Driving Standards Agency (DSA) know about their disability because they may be entitled to extra time for the test. Call: 0300 200 1122 or email: customerservices@dvsa.gov.uk.

If your child has an autistic spectrum condition, the National Autistic Society has information about learning to drive, as well as links to other resources to help you. To find out more go to: www.autism.org.uk/driving.

Access and mobility

Out of town

*The Rough Guide to Accessible Britain* is a good place to start looking at access across the UK. See their website, www.accessibleguide.co.uk.

The website www.disabledgo.com, is also useful and covers the whole of the UK and Ireland.

London can seem a challenging destination for disabled travellers, especially as many underground stations are unsuitable for disabled or wheelchair using passengers and there are no porters to help with luggage. The Transport for London (TfL) website offers thorough information about transport accessibility. Go to the section called ‘Getting Around’. They also publish a free guide called ‘Getting around London: your guide to accessibility’ which gives details of step-free stations, lifts, toilets and other useful information when travelling on the tube, buses and other forms of transport in the capital.
Travel and getting about

Shopmobility

This scheme operates in many city centres and shopping centres and means the disabled person can borrow a wheelchair or scooter. Some schemes also offer an escort to do the shopping. It's a popular scheme, so book early. You need to register before the first time you use it and there is a small charge for hire. Towns in West Sussex that run a shopmobility scheme include:

- Bognor tel: 01243 830077, or www.bognorshopmobility.co.uk.
- Chichester tel: 07932 802778, or go to: www.cfirst.org.uk/transport/individuals/shopmobility.
- Horsham tel: 01403 249015 or go to: www.horsham.gov.uk and search for ‘shopmobility’.
- Worthing tel: 01903 820980 or go to: www.worthingtowncentre.co.uk and search for ‘shopmobility’.

To find out about other schemes across the country, see the national Shopmobility website at www.nfsuk.org or call 01933 229644.

Air travel

If you are flying with a person with SEND, it does require some extra planning before you go, especially if your child is a wheelchair user or has reduced mobility, as it essential to request special assistance before you travel.

To find out what assistance is available, it’s best to check on the airport’s website well in advance of travelling and to ensure it has been booked via your airline or travel agent when you book your tickets. Special assistance must be requested at least 48 hours prior to your journey.

Gatwick: if you require an eagle hoist to transfer your child or young person from their wheelchair to their plane seat, this should be booked at least 24 hours before you travel by emailing: eaglehoist@gatwickairport.com.

Both terminals at Gatwick also have Changing Places accessible toilets. These are located after security for passengers arriving
and departing from the airport. An additional Changing Places facility located before security is also being planned for the South Terminal. For more information, to: www.gatwickairport.com. Choose ‘passenger services’ and click on ‘special assistance’.

**Heathrow** airport also provides special assistance, which must be requested 48 hours prior to travelling. For more, go to: www.heathrow.com/airport-guide/special-assistance. At the airport, you will find special assistance host areas in terminals 2 to 5. and Changing Places toilets located after security in terminals 2, 3, and 5 and in arrivals, terminal 4.

**Hidden Disability Assistance Programme**

**Gatwick** runs a ‘Hidden Disability Assistance Programme’ which is available to anyone with autism or other hidden disabilities who needs extra support and understanding at the airport. It provides special lanyards, which are a discreet way of flagging the wearer as someone who needs additional support from staff. The lanyards are available from Assistance Reception areas at the airport. You can also email the team at: HiddenDisability@gatwickairport.com before you travel. For more, go to the website: goo.gl/14J3FW.

Gatwick airport’s website also has a link to a downloadable booklet, *Our Autism-friendly visual guide to Travelling through Gatwick Airport*, with information, advice and photos of different parts of the airport. Go to: www.gatwickairport.com. Choose ‘passenger services’, then ‘special assistance’ and click on ‘hidden disabilities’.

Hidden disabilities lanyards are also available at **Heathrow**, go to: goo.gl/FmC8CY, **Stansted**: www.stanstedairport.com/help/special-assistance/hidden-disabilities and various regional airports such as **Birmingham** and **Luton**. To find out more, search for ‘hidden disability lanyard’ online.
Action Against Bullying Support Line (WSCC)

Telephone service for 13 to 19 year olds and their parents/carers, which can signpost to extra support and the Action Against Bullying team.

Tel: 0333 014 2904

Adults’ CarePoint

Social care support or advice for over 18s (for under 18s see the Multi-Agency Safeguarding Hub).

Tel: 01243 642121
Email: socialcare@westsussex.gov.uk

Benefit Enquiries

Attendance Allowance (AA)
Tel: 0800 731 0122
Textphone: 0800 731 0317
www.gov.uk/attendance-allowance

Carer’s Allowance Unit
Tel: 0800 731 0297
Textphone: 0800 731 0317
www.gov.uk/carers-allowance-unit

Disability Living Allowance (DLA) (for under 16s)
Tel: 0800 121 4600
Textphone: 0800 121 4523
www.gov.uk/disability-living-allowance-children

Personal Independence Payments (PIP) (for ages 16 to 64)
Tel: 0800 121 4433 (enquiries)
Tel: 0800 917 2222 (claims)
Textphone: 0800 121 4493 (enquiries)
Textphone: 0800 917 7777 (claims)
www.gov.uk/pip

Benefits Advisor

Advice and support for families who have children and young people with SEND to help them access Government benefits including DLA, PIP, Carer’s Allowance and Universal Credit.

Tel: 0330 222 2589 / 07850 240874
Email: robert.hayes@westsussex.gov.uk

For Blue Badge, see ‘Travel Directory’.
Carers Emergency Alert Card Scheme

Alerts people that you are a carer if you have an accident or fall ill so the person you care for can be looked after.

Tel: 01243 778688, email: chichestercareline@chichester.gov.uk
www.chichestercareline.org.uk

Changing Places

Fully accessible toilets with an adult-sized changing bench and a hoist. See website for toilet locations.

Tel: 020 7803 2876
Email: changingplaces@musculardystrophyuk.org
www.changing-places.org

Child and Adolescent Mental Health Services (CAMHS)

Referrals must be made by a professional from health, social care or an educational setting.

Tel: 0300 304 0100
Email: info@sussexpartnership.nhs.uk (general enquiries only)
www.sussexpartnership.nhs.uk/CAMHS

Citizens Advice

Free, independent, confidential and impartial advice on everything from benefits to money and debt, to housing, health and law. See website for webchat option.

Offices in: Burgess Hill; Crawley; East Grinstead; Haywards Heath; Horsham; Shoreham and Worthing.

Outreach centres:
Billingshurst; Broadfield; Henfield; Lancing; Pulborough; Roffey; Steyning and Storrington.

Advice Line: 0344 477 1171
TextRelay: 0344 411 1445
www.citizensadvice.org.uk

Community Equipment Service

Access to equipment is via a GP, occupational therapist, physiotherapist or community nurse. For delivery, collection, repair or servicing of equipment, contact NRS Healthcare on:

Tel: 0345 127 2931, email: customerservice@nrshealthcare.co.uk
www.sussexcommunity.nhs.uk/services/all-services.htm
### District and Borough Councils

- **Adur**
  - Tel: 01273 263000, email: helppoint@adur-worthing.gov.uk
  - [www.adur-worthing.gov.uk](http://www.adur-worthing.gov.uk)

- **Arun**
  - Tel: 01903 737500
  - Email: info@arun.gov.uk
  - [www.arun.gov.uk](http://www.arun.gov.uk)

- **Chichester**
  - Tel: 01243 785166
  - Email: contact@chichester.gov.uk
  - [www.chichester.gov.uk](http://www.chichester.gov.uk)

- **Crawley**
  - Tel: 01293 438000
  - Email: comments@crawley.gov.uk
  - [www.crawley.gov.uk](http://www.crawley.gov.uk)

- **Horsham**
  - Tel: 01403 215100
  - Email: contact@horsham.gov.uk
  - [www.horsham.gov.uk](http://www.horsham.gov.uk)

- **Mid-Sussex**
  - Tel: 01444 458166
  - Email: enquiries@midsussex.gov.uk
  - [www.midsussex.gov.uk](http://www.midsussex.gov.uk)

- **Worthing**
  - Tel: 01903 239999, email: enquiries@adur-worthing.gov.uk
  - [www.adur-worthing.gov.uk](http://www.adur-worthing.gov.uk)

### Family Fund

Offers financial support, including a ‘Driving Ambitions’ grant for learner drivers. See website for eligibility criteria.

- Tel: 01904 550055
- Email: info@familyfund.org.uk
- [www.familyfund.org.uk](http://www.familyfund.org.uk)

### Family Information Service (WSCC)

Run by West Sussex County Council to provide free up to date information for parents and carers, and young people aged up to 25.

- Tel: 01243 777807
- Email: family.info.service@westsussex.gov.uk
- [www.westsussex.gov.uk](http://www.westsussex.gov.uk)

### Hospitals with A&E departments

- **East Surrey Hospital**
  - Canada Ave, Redhill, Surrey, RH1 5RH

- **Princess Royal Hospital**
  - Lewes Road, Haywards Heath, RH16 4EX

- **Royal Sussex County Hospital**
  - Eastern Road, Brighton, BN2 5BE
St Richard’s Hospital
Spitalfield Lane, Chichester, PO19 6SE

Worthing Hospital
Lyndhurst Rd, Worthing, BN11 2DH

Jobcentre Plus

Helps people find jobs and/or claim benefits. Offices in Bognor Regis, Chichester, Crawley, Haywards Heath, Horsham, Littlehampton and Worthing.

Tel: 0800 169 0190
Textphone: 0800 169 0314, email: CONTACT-.DWP1@DWP.GSI.GOV.UK
www.gov.uk/contact-jobcentre-plus

Multi-Agency Safeguarding Hub (MASH) (WSCC)

For 0 to 18 years. For over 18s see the Adults’ CarePoint.

Single point of contact for all social care enquiries and safeguarding concerns regarding children and young people in West Sussex.

Tel: 01403 229900
Out of hours: 0330 222 6664, email: MASH@westsussex.gcsx.gov.uk
www.westsussexscb.org.uk/2016/04/multi-agency-safeguarding-hub-mash

NHS Choices

Official NHS website. Includes information on conditions, treatment and support services.

www.nhs.uk

NHS England

Sets the priorities and direction of the NHS in England.

Tel: 0300 311 2233
Email: england.contactus@nhs.net
www.england.nhs.uk

Occupational Therapy (OT)

Helps people with disabilities and other conditions to live more independently. Assessments can be requested through your GP or the Adults’ CarePoint, see page 216.

Out of Hours GP service

NHS non-emergency number. Tel: 111 (free from landline or mobile)

Preparing for Adulthood

Funded by the Department of Education, the website contains many resources to help parent carers and young people with SEND
prepare for adulthood. It includes the ‘Preparing for adulthood pathways’ that the Year 9 (transition) annual review paperwork is based on and a downloadable information pack.

Tel: 01225 789135, email: info@preparingforadulthood.org.uk
www.preparingforadulthood.org.uk

SEND Code of Practice (2015)
Statutory guidance for special educational needs and disabilities, including process for EHC Needs Assessments and EHC Plans.


SEND Information, Advice and Support Service (SEND IAS) (WSCC)
Tel: 0330 222 8555
Email: send.ias@westsussex.gov.uk
Young person’s advisor email: cyp.sendias@westsussex.gov.uk
https://westsussex.local-offer.org/services/7

SOS! SEN
Free, independent and confidential help for parents and others looking for information and advice on special educational needs provision. Helpline open term-time only.

Tel: 0300 302 3731 or 020 8538 3731
www.sossen.org.uk

West Sussex Connect to Support (WSCC)
Information and advice to help with independence and well-being with links to services, products, groups and activities in West Sussex.

Tel: 0333 600 6330
Email: info@shop4support.com
www.westsussex.gov.uk/social-care-and-health/west-sussex-connect-to-support

West Sussex County Council (WSCC)
Complaints and comments (ask for the customer relations team)
Tel: 01243 777100
Email: feedback@westsussex.gov.uk

Disabled Parking (Blue Badge scheme)
Tel: 01243 777653, email: blue.badges@westsussex.gov.uk

Family Information
Tel: 01243 777807, email: family.info.service@westsussex.gov.uk
www.facebook.com/FISWestSussex
General Enquiries  
Tel: 01243 777100  
Textphone (Type Talk): 018001 01243 777100  
www.westsussex.gov.uk/contact-us

Contact the Adult’s CarePoint for:  
• Rehabilitation Officers for the Visually Impaired (ROVIs)  
• Shared Lives Scheme  
• Social Care

West Sussex Local Offer (WSCC)  
For more, see page 4.

https://westsussex.local-offer.org

Wheelchair and Seating Service, West Sussex  
Assesses and provides wheelchairs and a seating to people with life-long and long-term disabilities. Please note that referrals must be made by health or social care. After a referral is accepted, people are registered with the service. For reassessment and advice you can then contact your local team on the numbers below.

Bognor  
(Covers Bognor Regis, Chichester, Harting, Littlehampton, Loxwood, Midhurst and Petworth)  
Tel: 01243 623650, email: sc-tr.wheelchairservicebognor@nhs.net

Horsham  
(Covers Burgess Hill, Copthorne, Crawley, East Grinstead, Haywards Heath, Horsham and Pulborough)  
Tel: 01403 227000 (Ext 7160), email: sc-tr.wheelchairservicehorsham@nhs.net

Worthing  
(Covers Findon, Henfield, Pulborough, Rustington, Shoreham, Southwick, Storrington and Worthing)  
Tel: 01273 265850, email: sc-tr.wheelchairserviceworthing@nhs.net

For repairs, contact:  
AJM Healthcare, Hailsham  
Tel: 01323 847250  
Email: service@ajmhealthcare.org
Local directory

For leisure activities, leisure centres, short breaks and buddy schemes, please refer to Chapter 4: Social life.

Note: listings marked (SB) are Short Breaks providers.

Action for Deafness

Provides advice, support, information and services to enable deaf, hard of hearing and deafblind people to lead independent lives.

Tel: 01444 415582
Email: info@actionfordeafness.org.uk
www.actionfordeafness.org.uk

Activus Sensory Room, Worthing

Sensory room with bubble tubes, infinity mirrors, and a hi-tech interactive floor projection. Please phone first to check the room has not been privately booked.

Tel: 01903 231117
Email: worthing@aquaterra.org
www.aquaterra.org/centre/activus-worthing/sensory-room

Advance

Teaches the Scotson Technique to improve breathing and posture in people with disabilities.

Tel: 01342 311137
Email: info@advancecentres.com
www.advancecentres.com

The Advocacy Service

Works directly with young people to ensure their wishes and feelings are heard and given weight in the decisions that adults (carers and professionals) make about their lives. Advocacy is independent, young person-led and issue based.

Tel: 0330 222 8686, email: AdvocacyService@westsussex.gov.uk

The Aldingbourne Trust

Individually tailored care and support for people with learning disabilities and their families. Offers a wide range of services from supported living to job training and life skills programmes.

Tel: 01243 544607
Email: info@aldingbourne.org
www.aldingbournetrust.co.uk

Allsorts

Support for young people aged 5 to 25 who are LGBTU (lesbian, gay, bisexual, trans, unsure) or questioning their sexuality or gender.
Offers an emotional support phone line called Talk It Out, and youth clubs in Horsham and Chichester.

Tel: 01273 721211
Email: youth@allsortsyouth.org.uk
www.allsortsyouth.org.uk/westsussex

**A Potential Diamond**

Initiative working with young people with autism or learning disabilities to maximise employment opportunities. Face-to-face support only offered to young people at Manor Green School or College. Young people at Crawley College might be supported if funding is approved via the college SENDCo.

Tel: 07738 941415
www.apotentialdiamond.org

**Apprenticeships in West Sussex**

Helps parent carers and young people search for apprenticeship training in the county.

Email: info@apprenticeships-in-west-sussex.com
www.apprenticeships-in-sussex.com/vacancies-west-sussex.php or:
www.westsussex.gov.uk/jobs/apprenticeships-career-tasters-and-volunteering/apprenticeships

**Arun Counselling (Littlehampton)**

Confidential counselling – no one is turned away if they cannot afford to pay. Mostly day-time appointments, but also offer evenings or Saturday mornings.

Tel: 01903 714417
www.aruncounselling.org.uk

**Aspens (formerly Autism Sussex)**

Charity supporting people with autism and a range of other disabilities, including complex needs.

Tel: 01892 822168
Email: enquiries@aspens.org.uk
childrenwsx@aspens.org.uk
familysupport@aspens.org.uk
www.aspens.org.uk

**Autism Support Crawley**

Support group for families of people who have autism or social communication difficulties. Also has a closed Facebook page – see website for details.

Tel: 07596 737741, email: admin@autismsupportcrawley.co.uk
www.autismsupportcrawley.co.uk
Barnardo’s Moving Forward Project

Offers a life skills youth group, ten weeks of individually tailored personal support, and/or fun days out for young people with SEND aged 16 to 25.

Tel: 01293 610692, email: moving.forward@barnardos.org.uk
www.barnardos.org.uk/moving-forward-project-west-sussex-health-life-skills/service-view.htm?id=261213804

Belltree Music Therapy Centre

The Belltree Music Therapy Centre offers a professional music therapy service to people of all ages across Brighton and Hove and Sussex.

Tel: 01273 776454
Email: info@belltree.org.uk
www.belltree.org.uk

Bevern Trust

Enabling people with profound disabilities live their lives to the full.

Tel: 01273 400752
Email: info@beverntrust.org
www.beverntrust.org

Blatchington Court Trust

Information, support, counselling and IT training for visually impaired people under the age of 30.

Tel: 01273 727222, email: info@blatchingtoncourt.org.uk
www.blatchingtoncourt.org.uk

Bright Futures Charity

Offers advice, support, training and information to adoptive parents and foster carers in Sussex.

www.brightfuturescharity.org.uk

The Butterfly Project

Supports adults with learning difficulties, autism and disabilities in work and community activities.

Tel: 01403 248580, email: admin@thebutterflyprojecthorsham.co.uk
www.facebook.com/TheButterflyProjectHorsham

Carers Support West Sussex

Free, confidential and impartial information and support to carers.

Tel: 0300 028 8888
Email: info@carerssupport.org.uk
www.carerssupport.org.uk
Chailey Heritage Clinical Services
Clinical care services for children with complex and multiple physical disabilities.
Tel: 01825 722112
Email: sc-tr.enquirieschcs@nhs.net
www.sussexcommunity.nhs.uk/chailey

Chailey Heritage Foundation
Offers a wide range of services to young adults with disabilities to optimise their potential. Includes the Future Life Skills Centre, day provision, accommodation and Futures Hub.
Tel: 01825 724444
Email: office@chf.org.uk
www.chf.org.uk/services-for-adults.html

Chestnut Tree House Children’s Hospice
Children’s hospice for children and young people aged 0 to 19 with progressive life-limiting or life-threatening illnesses.
Tel: 01903 871800, email: enquiries@chestnut-tree-house.org.uk
www.chestnut-tree-house.org.uk

Chichester Careline
Support services for carers including the Carers Emergency Alert Card.
Tel: 01243 778688, email: chichestercaerline@chichester.gov.uk
www.chichestercaerline.org.uk

Chichester Counselling Service
Affordable counselling for adults and young people aged 18+.
Tel: 01243 789200
Email: office@ccs-counselling.org.uk
www.ccs-counselling.org.uk

Chichester Down Syndrome Support Group
Support group for families of people with Down syndrome.
Tel: 07500 775596
Email: sussexrose@hotmail.co.uk
www.facebook.com/groups/chichesterds

Children and Young People’s Continence Team
A nurse-led team who provide a tier 2 targeted specialist continence service to children and young people. Supports families whose
children have ongoing difficulties with bladder or bowel control, constipation, withholding and other toileting issues.

Tel: 01273 242145, email: sc-tr.childrenscontinence@nhs.net

Children’s Continuing Care and Health-led Short Breaks

Nursing and care support at home for children with complex health needs, and health-led short breaks.

Tel: 01903 708455
Email: heather.mooney@nhs.net
www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16285

Coastal Enterprises

Day service for adults who have learning disabilities, focusing on support and developing independence.

Tel: 01903 239460, email: martin.fletcher@westsussex.gov.uk

Coastal West Sussex Mind

Mental health charity providing advice, support. Also runs training events for families of young people with ADHD and autism.

Tel: 01903 277000, email: info@coastalwestsussexmind.org
www.coastalwestsussexmind.org

Community Children’s Nursing Team

Home and community-based nursing for children and young people from birth to 19 years with complex health needs, life-threatening or life-limiting conditions and acute or long-term conditions.

Chichester: 01243 793619
Crawley: 01293 600300 ext. 3207
Worthing: 01273 696011 ext.6200
www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16348

Community Learning Disability Teams (CLDTs)

Specialist health and social care staff who support adults with learning disabilities and complex needs.

For Chichester and Bognor:
CLDT Western (Bognor)
Tel: 0330 222 7888, email: ctpld.western.duty@westsussex.gov.uk

For Littlehampton, Shoreham and Worthing:
CLDT Coastal (Worthing)
Tel: 0330 222 7778, email: ctpld.coastal.duty@westsussex.gov.uk
For Crawley, Horsham and Mid Sussex:
CLDT North (Horsham)
Tel: 01403 229129, email: cltld.north.duty@westsussex.gov.uk

Compass Card (Amaze)
Card for 0 to 25 year olds with SEND in West Sussex and Brighton & Hove, which can be used to get discounts or special offers at leisure venues.
Tel: 0300 123 9186, email: compass@amazesussex.org.uk
www.compasscard.org.uk

County Deaf Services
Advice, assessments and arranges specialist equipment for adults who are deaf or have hearing loss. For more, search the website below for ‘County Deaf Services’.
Tel: 01243 642121
SMS text: 07736 093462
Minicom: 01403 275515
Email: county.deaf.services@westsussex.gov.uk
www.westsussexconnecttosupport.org

Crossroads Care (SB)
Support and flexible day, evening and night services for children and adults with disabilities and health conditions. Also runs social clubs.
Tel: 01903 790270
Email: admin@crossroadscare-sc.org
www.crossroadscare-sc.org

Cruse Bereavement Care
Counselling, information and support to bereaved people.
Tel: 0808 808 1677 (central helpline)
Tel: 0300 311 9959 (West Sussex)
Email: westsussexarea@cruse.org.uk
www.cruse.org.uk

Dolphin House
Complementary, donation-based therapies for children and young people.
Tel: 01273 324790
Email: info@dolphinhouseclinic.com
www.dolphinhouseclinic.com

Facebook support groups
Use the search bar to find groups. Some hold face-to-face meet ups.

Autism by the Sea (Worthing)
Contact Clare Greaves, email: Greaves.clare@btinternet.com

Horsham Parent SEND Support
Contact Jane Cross
Email: Jcross@qe2.co.uk
PATH – Parenting Autism Together in Horsham
Contact Sarah Willis
Tel: 07588 460954
Email: benandsarahwillis@gmail.com

Reaching Families
Contact Brian O’Hagan
Tel: 07939 192388
Email: info@reachingfamilies.org.uk

Special Families East Grinstead
Contact Emma Bashford
Tel: 07928 135453, email: admin@specialfamilieseastgrinstead.org.uk
www.specialfamilieseastgrinstead.org.uk

Sussex Autism Support
Contact Katarina Wilmore
Tel: 07817 250995, email: sussexautismsupport@live.co.uk
www.sussexautismsupport.co.uk

West Sussex ADHD
Crawley tel: 07973 873651, email: crawley@adhdwestsussex.org
Worthing tel: 07765 262524 or 07875298976, email: worthing@adhdwestsussex.org

Fibromyalgia support group for Worthing and West Sussex
Support group for people with fibromyalgia, CFS and ME.

Tel: 0844 887 2394 or 07934 640814
Email: nicholaabond@gmail.com
www.fmswaws.org

Finches Short Breaks Centre
Respite breaks for children/young people with complex health needs in a fully adapted accessible bungalow.

Tel: 01444 245117
Email: sc-tr.enquirieschcs@nhs.net

FindItOut Centres
Information, advice and guidance for young people aged 13 to 25 years (11 to 12 with a parent/guardian).

Tel: 0330 222 2121

Adur
Lancing Youth Centre, Penhill Road, Lancing, BN15 8HA
Tel: 01903 763639

Bognor Regis
Church Path, Glamis Street, Bognor Regis, PO21 1DB
Tel: 01243 867430, email: FIO.BognorRegis@westsussex.gov.uk
Chichester
New Park Road, Chichester, PO19 7XY
Tel: 01243 538587
Email: ChichesterFIOCentre@westsussex.gov.uk

Crawley
Centenary House, County Buildings, Woodfield Road, Crawley, RH10 8GP
Tel: 01293 843327, email: alex.redford@westsussex.gov.uk

Horsham
Youth Hub@Horsham, Hurst Road, Horsham, RH12 2DN
Tel: 07523 500894, email: paula.lintott@westsussex.gov.uk

Littlehampton
82 Wick Street, Littlehampton BN17 7JS
Tel: 07718 322346, email: vicki.goodland@westsussex.gov.uk

Mid Sussex
Park Centre, 60 Park Road, Burgess Hill, RH15 8ET
Tel: 01444 243922, email: madeline.scutt@westsussex.gov.uk

Worthing
The Place, 24 Marine Place, Worthing, BN11 3DN
Tel: 01903 210315

Food Banks see Local Assistance Network

Healthwatch West Sussex
For information, see page 157.
Tel: 0300 012 0122, email: helpdesk@healthwatchwestsussex.co.uk
www.healthwatchwestsussex.co.uk

HOPE Charity Project
Supports young people with mental health issues and their families.
Services include, 1-1 and group/family counselling, animal and creative therapies.
www.hopecharityproject.org

Hyperactive Children’s Support Group (HACSG)
Information and training for families of children and young people who have ADHD or are hyperactive.
Tel: 01243 539966
Email: hacsg@hacsg.org.uk
www.hacsg.org.uk

Independent Complaints Advocacy Service
For information, see page 158.
Tel: 0300 012 0122, email: helpdesk@healthwatchwestsussex.co.uk
Independent Lives

Information, care and support services to enable people with care needs to be independent.

Tel: 01903 219482, email: feedback@independentlives.org
www.independentlives.org

Interactive Room, Littlehampton Swimming & Sports Centre

Interactive room includes dance mats, sensory lights, games and a DJ sound system.

Tel: 01903 725451
www.freedom-leisure.co.uk

IPEH Worth Specialist Domestic Abuse Service (WSCC)

Support service for people at high risk of harm due to domestic abuse.

Tel: 07834 968539 / 0330 222 8181
Email: domesticAbuseServicesCentral@westsussex.gov.uk
www.westsussex.gov.uk/fire-emergencies-and-crime/domestic-abuse

Learning Assessment and Neurocare Centre (LANC)

Works with children, young people and adults with complex neurodevelopmental difficulties.

Tel: 01403 240002 or 01403 260900
Email: info@lanc.uk.com
www.lanc.org.uk

Learning Disabilities Health Facilitation Team (NHS)

Nursing team specialising in health care for people with learning disabilities.

Tel: 01403 227000 (ext 7341)
www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16352

Local Assistance Network (LAN)

Short-term practical aid, such as food banks or recycled furniture, for people who have no other means of assistance in a crisis.

Learning and Behaviour Advisory Team (LBAT) (WSCC)

Supports children up to the age of 16, their families and schools where learning and/or behaviour difficulties are affecting progress.

Email:
helen.cottell@westsussex.gov.uk
https://westsussex.local-offer.org/services/229

Local directory
Adur - Worthing Churches Homeless Projects
1a New Road, Shoreham-by-Sea
BN43 6RA
Tel: 01903 680748
Email: lan@wchp.org.uk
www.wchp.org.uk/what-we-do/
local-assistance-network-lan

Chichester & Arun – Stonepillow
Stonepillow Restore, Unit 3, Plot 27,
Terminus Road, Chichester
PO19 8UE
Tel: 01243 213411, email:
localassistance@stonepillow.org.uk
http://stonepillow.org.uk/projects/
local-assistance

Crawley district – Crawley Open House
Riverside House, Stephenson Way,
Three Bridges, Crawley, RH10 1TN
Tel: 01293 447702
Email: senioradvice@
crawleyopenhouse.co.uk
www.crawleyopenhouse.co.uk/
advice-and-lan

Horsham district – Horsham Matters
Micah House, Blatchford Road,
Horsham, RH13 5QR
Tel: 0300 124 0204, email:
support@horsham-matters.org.uk
http://horsham-matters.org.uk/
needhelp

Littlehampton – Worthing Churches Homeless Projects
Littlehampton United Church, 1 High
Street, Littlehampton, BN17 5EG
Tel: 07702 872377, email:
lantlittlehampton@wchp.org.uk
www.wchp.org.uk/what-we-do/
local-assistance-network-lan

Worthing - Worthing Churches Homeless Projects
6-8 Marine Place, Worthing
BN11 3DN
Tel: 01903 680748
Email: lan@wchp.org.uk
www.wchp.org.uk/what-we-do/
local-assistance-network-lan

UK Foodbank Network
(The Trussell Trust)
Phone to be put in touch with your
nearest foodbank, or search online.
Tel: 01722 580180
Email: enquiries@trusselltrust.org
www.trusselltrust.org/get-help/find-a-foodbank

Look Sussex
Support and events for the families
of children and young people with
a visual impairment in Sussex. Also
runs a youth club. Search for Look
Sussex on Facebook.

Tel: 07703 434119
Email: Tara.dutton@btinternet.com
http://looksussex.org.uk
Mid-Sussex Mencap
Provides support, social activities and funding to local people with learning disabilities.
Tel: 01444 471431, email: chair@midsussexmencap.org.uk
www.midsussexmencap.org.uk

MIND
Information and support around mental health issues. Has advocacy workers who can support young people/adults in West Sussex.
Tel: 01273 666950
Email: info@mindcharity.co.uk
www.mindcharity.co.uk

Money Advice Plus
Counselling, advice and support to people in Sussex who are having trouble managing their finances.
Tel: 01273 664000
Email: info@moneyadviceplus.org.uk
www.moneyadviceplus.org.uk

Oak Community Project,
Rustington (WSCC)
Community-focused day service for adults with learning disabilities, providing assessed care within a structured programme of activities.
Tel: 01903 779739, email: chris.hughes@westsussex.gov.uk
www.facebook.com/oakcommunityproject

Offington Counselling Service
(Worthing)
Confidential counselling service set up for people who could not otherwise afford it.
Tel: 01903 212275
Email: info@ocs-counselling.org.uk
www.ocs-counselling.org.uk

Olive Tree Cottage
Café and garden run by a family who have children with special needs. Sensory area, ducks and rabbits, wheelchair friendly. Check Facebook for opening days/times.
40 Links Avenue, Felpham, PO22 7BX
Tel: 07496 076846
Email: sjsotc@yahoo.com
www.facebook.com/friendsofolivetreecottage

Outreach 3 Way
Runs leisure and sports activities, a day centre and offers flexible support to young people and adults with learning disabilities and/or autism.
Outset Youth Action

A county-wide charity that acts as a volunteering agency for young people aged 13 to 25 years. Also helps young people with severe disadvantages to move into work.

Tel: 01798 831153
Email: info@outsetyouth.org.uk
www.outsetyouth.org.uk

Patient Advice and Liaison Service (PALS)

Information and advice service (including complaints) for NHS patients. Hospitals and NHS services have been listed by NHS trust.

Brighton and Sussex University Hospitals:

Princess Royal Hospital, Haywards Heath
Tel: 01444 448678

Royal Alexandra Children’s Hospital, Brighton
Tel: 01273 696955

Royal Sussex County Hospital, Brighton
Tel: 01273 664511 or 01273 664973.

Email: PALS@bsuh.nhs.uk
www.bsuh.nhs.uk/your-visit/help-and-support/patient-advice-and-liaison-service-pals

Surrey and Sussex Healthcare NHS Trust

East Surrey Hospital
Tel: 01737 231 958
Email: pals@sash.nhs.uk
www.surreyandsussex.nhs.uk/patients-visitors/pals

Sussex Partnership NHS Foundation Trust

Tel: 0300 304 2198, email: pals@sussexpartnership.nhs.uk

Western Sussex Hospitals:

St Richard’s Hospital, Chichester
Tel: 01243 831822
Email: PALSChichester@wsht.nhs.uk

Worthing and Southlands Hospital
Tel: 01903 285032
Email: PALSWorthing@wsht.nhs.uk

www.westernsussexhospitals.nhs.uk/services/patient-advice-and-liaison-service-pals-complaints/
Pegasus card scheme
(Sussex Police)

Card for people with disabilities or communication difficulties. It alerts emergency services that the holder needs additional help or support.

https://sussex.police.uk/contact-us/accessible-contact-methods/pegasus-scheme

Phoenix Centre Sensory Room
(Bognor Regis)

A fully equipped sensory room for people with special needs.

Tel: 01243 840075, email: Thephoenixcentre@westsussex.gov.uk
www.theregisschool.co.uk/phoenix-youth-centre

Puzzle Pieces (Bognor)

Parent-led group for parents with children and young people on the autistic spectrum. Meets at Treehouse Children and Family Centre, Bognor.

Tel: 01243 642917, email: treehouse.cfc@westsussex.gov.uk

Rainbow Trust Children’s Charity

Emotional and practical support for families of children aged 0 to 18 years with life-threatening or life-limiting conditions.

Tel: 01372 220111, email: enquiries@rainbowtrust.org.uk
www.rainbowtrust.org.uk

Reaching Families

For more, see page 5.

Tel: 07939 192388
Email: info@reachingfamilies.org.uk
www.reachingfamilies.org.uk

Rehabilitation Engineering Service
(Chailey Clinical Services)

Provides a range of rehabilitation engineering services to children and young people with complex physical disabilities to maximise their independence and safety.

Tel: 01825 722112
Email: kaylee.nicholas@nhs.net
www.sussexcommunity.nhs.uk/services/chailey/res.htm
Relate Sussex

Counselling for parents, carers, couples, families, children and young people.

Chichester – Tel: 01243 788935, email: reception.crawley@relatesussex.org

Crawley – Tel: 01293 657055, email: reception.crawley@relatesussex.org

East Grinstead – Tel: 01293 657055
Email: reception.crawley@relatesussex.org

Haywards Heath – Tel: 01273 697997
Email: reception@brightonrelate.org.uk

Horsham - Tel: 01403 266454, email: reception.crawley@relatesussex.org

Worthing – Tel: 01903 202512, email: worthing@brightonrelate.org.uk

www.relate.org.uk

Email: jo@samaritans.org
www.samaritans.org

Scope West Sussex

Leisure and social activities for people 18 to 50 with physical and sensory disabilities.

Tel: 01243 775330, email: info@scope-west-sussex.org.uk
www.scope-west-sussex.org.uk

SEND Youth Voice

Gives young people aged 11 to 25 with SEND chance to share their views and help to shape future services.

Tel: 07734 000401, email: rachel.sadler@westsussex.gov.uk
www.rixwiki.org/west-sussex-mmm/home/youth-participation-1

Sensory Support Team

Supports children and young people aged 0 to 19 years who have hearing, visual or multi-sensory needs.

Tel: 01903 270430, email: sensory.support@westsussex.gov.uk

Samaritans of Horsham and Crawley

Trained volunteers run a free 24-hour helpline for people to call to talk through problems. You can also drop in to the Horsham branch.

21 Denne Road, Horsham, RH12 1JE
Tel: 01403 276276 (local rate)
National support line: 116 123 (free)
Signposts
Information, advice and training to people with learning difficulties and their parents/carers.
Tel: 01444 616232, email: info@signpostsmidsussex.org.uk
www.signpostsmidsussex.org.uk

Single Parent Information Network (SPIN)
Information, support, networking, and social events for single parents in Brighton and Sussex.
Tel: 07948 971559
Email: SPIN@live.co.uk
http://groupspaces.com/SPINBRIGHTON

Smile Support and Care
One-to-one care for families with disabled children and young adults.
Tel: 01903 723333
Email: sussex.enquiries@smilesupport.org.uk
www.smilesupport.org.uk

SNAPS
Drop-in support group for parents and carers of children with special needs aged 0 to 16. Held at St Matthew’s church in Worthing.
Tel: 01903 207024
www.stmatthewsworthing.co.uk

Sussex Against Bullying
(Bognor Regis)
Youth club and holiday scheme for young people aged 11 to 18 who have been affected by bullying.
Tel: 07578 534933
Email: info@sussexab.org
www.sussexab.org.uk

Sussex Association for Spina Bifida and Hydrocephalus (SASBAH)
For people with spina bifida and/or hydrocephalus and their families. Includes activities, a family programme, youth club, welfare assistance and advice.
Tel: 01903 230782
Email: zoe@sasbah.org.uk
www.sasbah.org.uk

Sussex Deaf Association
Support, social, welfare services and facilities for deaf, deafblind, deafened and hard of hearing people across Sussex.
Tel/Minicom: 01273 671899
SMS Text: 07958 655117
Email: info@sussexdeaf.com
www.sussexdeaf.com

**Sussex Mental Health Line (NHS)**

Offers support and signposting to further help.

Tel: 0300 500 0101
www.sussexpartnership.nhs.uk/urgent-help-crisis

**Sussex Snowdrop Trust**

Provides equipment, nursing support, and volunteers to families of children with life-threatening or terminal illnesses.

Tel: 01243 572433
Email: info@snowdroptrust.com
www.thesussexsnowdroptrust.com

**Umbrellas**

SEND support groups run by Reaching Families in West Sussex.

Billingshurst
Tel: 07305 053237, email: rebecca@reachingfamilies.org.uk

Littlehampton
Tel: 07704 037664, email: rosemary@reachingfamilies.org.uk

Worthing
Tel: 07704 037664, email: rosemary@reachingfamilies.org.uk
www.reachingfamilies.org.uk/umbrellas.htm

**WEA Reaching Out Programme, Chichester**

Runs courses for adults with learning disabilities and other additional needs, such as yoga, tai chi and art.

Tel: 01243 551683
Email: anne.hollis@briarlodge.me.uk

**Wellspring**

Information, services and resources for children and young people with disabilities and their families.

Tel: 07742 408868, email: lizzie@wellspringwestsussex.org.uk
www.wellspringwestsussex.org.uk

**West Sussex ADHD Support**

A parent-led volunteer group, supporting individuals of all ages with ADHD in West Sussex.
Crawley
Tel: 07973 873651, email: crawley@adhdwestsussex.org
www.facebook.com/groups/CrawleyADHD

Worthing
Tel: 07765 262524 or 07875298976
Email: worthing@adhdwestsussex.org
www.facebook.com/groups/worthingADHD

West Sussex Circles Project
Advocacy, inclusion and support for people who are isolated or at risk of being isolated.
Tel: 01444 236593 (Burgess Hill)
Tel: 01293 512257 (Crawley)
Email: info.southeast@circlesnetwork.org.uk
www.circlesnetwork.org.uk

West Sussex Parent Carer Forum
Parent-led forum providing information, support and training to parent carers to help them to participate in shaping local services.
Tel: 01903 726188
Email: office@wspcf.org.uk
www.wspcf.org.uk

Winston’s Wish
National charity with a branch in Hove providing support for bereaved children and young people up to the age of 18.
Tel: 0808 802 0021 (helpline)
Tel: 01273 805035 (Hove)
www.winstonswish.org
http://help2makesense.org
(for bereaved young people)

Worthing & District Scope
Day centre, social activities, grant scheme, housing, and more for young people and adults with disabilities – cerebral palsy in particular.
Tel: 01903 522366, email: admin@worthingscope.org.uk
www.worthingscope.org.uk

Worthing Mencap
For people with learning disabilities and their families. Services include a drop-in centre, information hub, day centre, work placements in Buddys Café, sports club and activities.
Tel: 01903 202030, email: buddys@worthingmencap.org
www.worthingmencap.org
**Young Carers (WSCC)**

Supports for young carers and their families.

Tel: 01903 270300, email: youngcarers@westsussex.gov.uk  
www.westsussex.gov.uk/education-children-and-families/young-carers

**Your Space (WSCC)**

Advice and support for young people aged 13 to 25 years on everything from careers to relationships.

www.westsussex.gov.uk/education-children-and-families/your-space

**Youth Emotional Support (YES) (WSCC)**

Support and counselling for young people aged 11 to 18 with mental health issues such as depression, anxiety and self-harm. For more, go to the link below and click on ‘emotional wellbeing’

Tel: 0330 222 6711  
Email: emotionalwellbeing.yps@westsussex.gcsx.gov.uk  
www.westsussex.gov.uk/education-children-and-families/your-space/health
AbilityNet

Helps children and adults with disabilities use computers and access the internet.

Tel: 0800 269 545 or 01926 312847
Email: enquiries@abilitynet.org.uk
www.abilitynet.org.uk

Accessible Property Register

Website listing accessible and adapted property for sale and rent, including holiday lets.

Tel: 0800 368 9228, email: info@accessible-property.org.uk
www.accessible-property.org.uk

Access to Work

For more, see page 174.

Tel: 0800 121 7479
Textphone: 0800 121 7579
BSL relay service – see website
www.gov.uk/access-to-work

Action Against Medical Accidents (AvMA)

Charity providing free independent advice and support to people affected by medical accidents.

Tel: 0845 123 2352 (helpline)
www.avma.org.uk

Action for All Speech Impaired Children (AFASIC)

Supports families of children and young people with speech, language and communication needs (SLCN).

Tel: 0300 666 9410
www.afasic.org.uk

Action for ME

Provides information, support and advice to people with ME and chronic fatigue syndrome (CFS).

Tel: 0171 927 9551, email: questions@actionforme.org.uk
www.actionforme.org.uk

Action for Sick Children

Support and campaigning to improve health care for sick children and young people.

Tel: 0161 486 6788
Email: gill@a4sc.org
www.actionforsickchildren.org

Action on Hearing Loss

Information, advice, hearing checks, equipment and campaigning on behalf of people with hearing impairments.

Tel: 0808 808 0123
Textphone: 0808 808 9000
SMS: 07800 000360, email: informationline@hearingloss.org.uk
www.actiononhearingloss.org.uk

**Activity Alliance** (formerly English Federation of Disability Sport)

Helps disabled people to lead active lives and sports organisations to be as inclusive as possible.

Tel: 01509 227750
www.activityalliance.org.uk

**AIDIS Trust**, see **Everyone Can**

**Ambitious about Autism**

Education, training and campaigning for improved opportunities for people with autism.

Tel: 020 8815 5444, email: info@ambitiousaboutautism.org.uk
www.ambitiousaboutautism.org.uk

**Anti-Bullying Alliance**

Has a SEND Information Hub with resources and signposts to further support.

Email: aba@ncb.org.uk
www.anti-bullyingalliance.org.uk

**Arthritis Care**

Information, training and networking for people with arthritis.

Tel: 0808 800 4050
Email: info@arthritiscare.org.uk
www.arthritiscare.org.uk

**Asian People’s Disability Alliance (APDA)**

Information, advice, day care, sports and arts for disabled Asian people.

Tel: 020 8459 1030
Email: info@apda.org.uk
www.apda.org.uk

**Association for Real Change (ARC)**

Information, advice and training and consultancy on person-centred services for people with learning disabilities.

Tel: 01246 555043
Email: contact.us@arcuk.org.uk
www.arcuk.org.uk

**Association for Rehabilitation of Communication and Oral Skills (ARCOS)**

Information, advice and therapy for people with communication and/or swallowing problems.

Tel: 01684 576795
Email: admin@arcos.org.uk
www.arcos.org.uk
**Asthma UK**

Information, advice, research and campaigning on behalf of people with asthma.

Tel: 0300 222 5800  
Email: info@asthma.org.uk  
www.asthma.org.uk

**Attention Deficit Disorder Information and Support Service (ADDISS)**

Information, advice and training for people with ADHD/ADD and their carers/families.

Tel: 020 8952 2800  
Email: info@addiss.co.uk  
www.addiss.co.uk

**Barnardo’s**

For disabled children and young people and their families. Offers short breaks, crisis intervention, holiday schemes, education advice and support for young carers.

Tel: 01293 610660 (regional office)  
www.barnardos.org.uk

**Beat**

Support for anyone with an eating disorder.

For under 18s:  
Tel: 0808 801 0711 (youthline), email: fyp@beateatingdisorders.org.uk

For over 18s  
Tel: 0808 801 0677 (helpline), email: help@beateatingdisorders.org.uk  
www.beateatingdisorders.org.uk

For all students  
Tel: 0808 801 0811, email: studentline@beateatingdisorders.org.uk

**Brain and Spine Foundation**

Information, advice and training for people affected by brain and spine conditions, medical and educational professionals.

Helpline: 0808 808 1000  
Email: info@brainandspine.org.uk  
www.brainandspine.org.uk

**British Association for Counselling and Psychotherapy (BACP)**

Membership organisation governing the professional standards of counsellors and psychotherapists.

Tel: 01455 883300  
Email: bacp@bacp.co.uk  
www.bacp.co.uk
British Association for Supported Employment (BASE)

Information and advice for jobseekers with disabilities, including support when you have a job and advising employers on adjustments. Also has information on supported internships, apprenticeships and other government schemes.

Tel: 01204 880733
Email: admin@base-uk.org
www.base-uk.org

British Deaf Association

Deaf-led membership organisation that campaigns for greater equality for deaf people. Also runs an advocacy service.

Tel: 020 7697 4140
SMS: 07795 410724
Email: bda@bda.org.uk
www.bda.org.uk

British Dyslexia Association

Information, advice and training for people with dyslexia, their families and professionals.

Tel: 0333 405 4567
www.bdadyslexia.org.uk

British Institute for Brain Injured Children (BIBIC)

Assessment, therapy and support for children and young people up to the age of 25 who have brain injuries or conditions such as autism, ADHD, learning disabilities and cerebral palsy. Includes support to develop independence and self-care skills.

Tel: 01458 253344
Email: info@bibic.org.uk
www.bibic.org.uk

British Pregnancy Advisory Service (BPAS)

Organisation offering information, counselling and treatment for those who are pregnant.

Tel: 0345 730 4030
Email: info@bpas.org
www.bpas.org

Brittle Bone Society

Supports people with brittle bone disease (Osteogenesis Imperfecta) and their families.

Tel: 01382 204446
Email: bbs@brittlebone.org
www.brittlebone.org
Brook

Information, advice and support on sexual health for under 25s, including contraception.

www.brook.org.uk

Campaign Against Living Miserably (CALM)

Aims to prevent male suicide. Runs a helpline (below) for men who are feeling down or need to talk. See website for webchat helpline.

Tel: 0800 585858
Email: info@thecalmzone.net (general enquiries only)
www.thecalmzone.net

Carers UK

Information, advice and campaigning on behalf of all unpaid carers.

Helpline: 0808 808 7777
Email: adviceline@carersuk.org
www.carersuk.org

CEA card, see page 74

Cerebra

Information and advice, a postal lending library, speech therapy, grants and parent-to-parent support for families of children aged 16 and under with brain-related conditions.

Tel: 0800 328 1159
Email: info@cerebra.org.uk
www.cerebra.org.uk

Challenging Behaviour Foundation

Information and advice for families and those working with people with severe learning disabilities whose behaviour challenges.

Tel: 0300 666 0126
Email: support@thecbf.org.uk
www.challengingbehaviour.org.uk
Changing Faces

Campaigns for and offers care and support to individuals and their families who have a condition or injury that affects their appearance.

Tel: 0300 012 0275, email: support@changingfaces.org.uk
www.changingfaces.org.uk

Charlotte’s Tandems

Loans tandems, tag-alongs and other equipment free of charge exclusively to people with disabilities or additional needs who are unable to ride a bike safely on their own.

www.charlottestandems.co.uk
www.facebook.com/groups/CharlottesTandems

Child Bereavement UK

Information and support for families and young people, plus training to professionals working with families who have lost a child or when a child is bereaved.

Tel: 0800 028 8840, email: support@childbereavementuk.org
www.childbereavementuk.org

Child Brain Injury Trust (CBIT)

Family support, information, advice and training to families of children and young people with acquired brain injuries.

Tel: 0303 303 2248
Email: info@cbituk.org
www.childbraininjurytrust.org.uk

Child Death Helpline

Freephone service staffed by volunteers for anyone affected by the death of a child, whether it occurred pre-birth, in childhood or adulthood.

Tel: 0800 282 986 (from a landline)
Tel: 0808 800 6019 (from mobile)
Email: contact@childdeathhelpline.org
www.childdeathhelpline.org.uk

Child Law Advice Service

Intensive support phone lines for complex matters and clarifying questions. Run by the Coram Children’s Legal Centre. Suggests people read the terms and conditions on the website before calling or messaging via the site.

Tel: 0300 330 5480 (family or child law)
Tel: 0300 330 5485 (education law)
https://childlawadvice.org.uk
Child Maintenance Service

Government agency that seeks to ensure parents who live apart from their children contribute financially to their upkeep.

Tel: 0345 266 8792
Textphone: 0345 266 8795

https://childmaintenanceservice.direct.gov.uk/public

Children’s Heart Association

Support group run by and for the family and friends of children and young people with heart disorders.

Tel: 01706 221988
Email: information@heartchild.info
https://heartchild.info

Children’s Heart Federation

Information, advice and grants for families of children and young people with heart conditions.

Tel: 0808 808 5000
Email: info@chfed.org.uk
www.chfed.org.uk

Circles Network

Works with people of any age who are isolated or at risk of isolation.

Can help with circles of support, independent and collective advocacy and person-centred planning.

Tel: 01788 816671
Email: info@circlesnetwork.org.uk
www.circlesnetwork.org.uk

Cleft Lip and Palate Association (CLAPA)

Information on activities for children and young people, advice on treatment and offers peer support and volunteering opportunities.

Tel: 020 7833 4883
Email: info@clapa.com
www.clapa.com

The Compassionate Friends

Charity run by bereaved parents offering support to parents, grandparents and siblings who have lost a child of any age.

Tel: 0345 123 2304
Email: helpline@tcf.org.uk
www.tcf.org.uk

Computers for the Disabled

Information, advice and the provision of recycled computers to disabled people and organisations.
Contact (formerly Contact a Family)

Supports families of disabled children and professionals. Website has online information, advice, resources on conditions and a chat forum.

Tel: 0808 808 3555
Email: info@contact.org.uk
https://contact.org.uk

Coram Children’s Legal Centre

Provides legal advice, information and representation where possible for children, young people and families in cases relating to social services and community care.

Email: info@corumclc.org.uk
www.childrenslegalcentre.com

Council for Disabled Children

Umbrella organisation for England’s disabled children’s sector, bringing together professionals, practitioners and policymakers. Online resources for parent carers, young people and professionals. Supports local authorities to ensure parents and young people have access to IAS services. Runs the Transition Network providing information on moving to adulthood for young people and professionals and Making Ourselves Heard, focusing on participation of disabled children and young people.

Email: cdc@ncb.org.uk
www.councilfordisabledchildren.org.uk

Cystic Fibrosis Trust

Information and advice, care and support, grants, research and campaigning on behalf of people with cystic fibrosis.

Tel: 0300 373 1000 or 020 3795 2184
Email: helpline@cysticfibrosis.org.uk
www.cysticfibrosis.org.uk

DES (Disability Equipment Service) (formerly AskDES)

National website for buying and selling of new and used disability aids and equipment.

Tel/SMS: 07845 041678,
https://disabilityequipmentservice.co.uk

Diabetes UK

Information and advice, training, advocacy, support groups and campaigning on behalf of people affected by diabetes.
National directory

Disability Law Service
Disabled-run organisation providing free legal advice and representation in specific areas of law – check website for more information.
Tel: 020 7791 9800
Email: advice@dls.org.uk
www.dls.org.uk

Disability, Pregnancy and Parenthood
Practical information and peer support online for disabled parents, with articles from parents sharing their personal experiences.
Email: info@disabledparent.org.uk
www.disabledparent.org.uk

Disability Rights UK
Information and advice for disabled people, including fact sheets on benefits, independent living and equality. Also runs the Equality Advisory Support Service, see below.

Disabled Students’ Helpline
Tel: 0330 995 0414, email: students@disabilityrightsuk.org

Personal Budgets helpline
Tel: 0330 995 0404, email: personalbudgets@disabilityrightsuk.org
www.disabilityrightsuk.org

Disabled Living Foundation
Provides information, advice and training on daily living aids.
Tel: 0300 999 0004
Email: info@dls.org.uk
www.dls.org.uk

Down’s Heart Group
Provides information and advice to families whose children congenital heart defects associated with Down syndrome.
Tel: 0300 102 1644
Email: info@dhg.org.uk
www.dhg.org.uk

Down’s Syndrome Association
Organisation that provides support, advice and information about all aspects of Down syndrome, including employment, transition to adulthood and benefits.
Tel: 0333 1212 300, email: info@downs-syndrome.org.uk
www.downs-syndrome.org.uk
Dyspraxia Foundation

Information, advice and training for people with dyspraxia, their parents, families and professionals.

Tel: 01462 454986, email: info@dyspraxiafoundation.org.uk
www.dyspraxiafoundation.org.uk

Epilepsy Action

Information, advice, support and campaigning on behalf of people with epilepsy.

Tel: 0808 800 5050
Email: helpline@epilepsy.org.uk
www.epilepsy.org.uk

Equality Advisory and Support Service (EASS)

Promotes and monitors human rights and equality, also offers advice on issues relating to them. Website has a live chat option.

Tel: 0808 800 0082
Textphone: 0808 800 0084
www.equalityadvisoryservice.com

Equality and Human Rights Commission

Challenges discrimination and protects and promotes human rights. Has information about rights under the Equality Act 2010. NB: For advice and support contact the EASS, above.

www.equalityhumanrights.com

ERIC, The Children’s Bowel and Bladder Charity

Information, advice and support to parents of children with continence issues and to health professionals.

Tel: 0845 370 8008
Email: helpline@eric.org.uk
www.eric.org.uk

Everyone Can (formerly AIDIS Trust)

Helps people with disabilities to improve their quality of life through the power of technology. Includes a gaming service.

Tel: 0808 800 0009
www.everyonecan.org.uk

Family Lives

Information, advice and support to parents and families.

Tel: 0808 800 2222
www.familylives.org.uk
Family Rights Group
Advises, advocates and campaigns for families involved with or requiring social care services.
Tel: 0808 801 0366
www.frg.org.uk

Foundation for People with Learning Disabilities
Supports organisations by providing information, training and advice to those working with people with learning disabilities. Publishes easy read guides on a number of topics as well as resources for families and professionals.
Tel: 020 7803 1100
www.mentalhealth.org.uk/learning-disabilities

Fragile X Society
Information, advice, resources and peer support to families of children with Fragile X Syndrome.
Tel: 01371 875100
Email: info@fragilex.org.uk
www.fragilex.org.uk

FRANK
Confidential advice about drugs, with live chat available on their website.
Tel: 0300 123 6600
Text: 82111
Email: frank@talktofrank.com
www.talktofrank.com

Gingerbread
Information, advice, training and local groups for single and lone parents. Includes benefits advice for parents whose children are school or college leavers.
Tel: 0808 802 0925
www.gingerbread.org.uk

Go Kids Go!
Provides wheelchair skills training to children and young people across the UK.
Tel: 01482 887163
Email: roy@go-kids-go.org.uk
www.go-kids-go.org.uk

Grandparents Plus
Support and advice for grandparents, especially those in a caring role.
Tel: 0300 123 7015, email: advice@grandparentsplus.org.uk
www.grandparentsplus.org.uk/disability
Guide Dogs

Information, advice and a range of services for young people with vision impairments, including buddy dogs, recreational activities and grants for assistive technology.

Young people’s services
Tel: 0800 781 1444, email: cypservices@guidedogs.org.uk

Adult services
Tel: (from landlines only) 0345 1430229
Email: london@guidedogs.org.uk
www.guidedogs.org.uk

Headway

Information, advice, local groups and campaigning on behalf of people affected by brain injuries.

Tel: 0808 800 2244
Email: helpline@headway.org.uk
www.headway.org.uk

Heartline

Information, advice and peer support for parents of children with a heart disorder. Provides activity weekends for young people aged 9 to 17, and subsidised caravan holidays for families.

Email: intouch@heartline.org.uk
www.heartline.org.uk

HemiHelp

Information sheets, education packs, handbook and Facebook group for children and young people with hemiplegia and their families. Support services are now provided by Contact on the number and email address below.

Tel: 020 7608 8700
Email: info@contact.org.uk
www.hemihelp.org.uk
www.facebook.com/groups/5512952137

Henry Spink Foundation

Information and resources on conventional and complementary therapies and research for a wide range of disabilities and conditions.

www.henryspink.org

Hft (previously Home Farm Trust)

National charity providing support services for people with learning disabilities and autism.

Tel: 0117 906 1700 / 01243 542714
Email: HftSussex@hft.org.uk
www.hft.org.uk
Home Ownership for People with Long-term Disabilities (HOLD)

For more information, see page 196.

Tel: 0333 321 4044
Email: helptobuyeastandsoutheast@bpha.org.uk
www.helptobuyese.org.uk/help-to-buy/hold

Information, Advice and Support Services (IAS Services)

Umbrella organisation representing and supporting local information advice and support services.

Email: iassn@ncb.org.uk
https://councilfordisabledchildren.org.uk/information-advice-and-support-services-network
https://cyp.iassnetwork.org.uk (for under 25s)

Kidney Care UK

Advice, support, counselling, advocacy and financial assistance for kidney patients and their families.

Tel: 01420 541424
Email: info@kidneycareuk.org
www.kidneycareuk.org

LawStuff

A website run by Coram Children’s Legal Centre giving free legal information to children and young people. Check their website to see if your query can be answered there, if not get in touch using the phone numbers below.

Family and child law queries
Tel: 0300 330 5480
Education law queries
Tel: 0300 330 5485
https://lawstuff.org.uk

Little Blue Cup

Helps families of children and adults with SEND to replace discontinued cups, toys, clothing and other small essentials that they rely on.

Email: marc@littlebluecup.org
www.facebook.com/LittleBlueCup

Local Government and Social Care Ombudsman

If you have complained to your local council, social care or another local public service provider and the problem hasn’t been put right, or sorted within 12 weeks, you can make a complaint to the Local Government and Social Care Ombudsman, who will investigate.
Tel: 0300 061 0614
Text ‘call back’ to: 07624 811595
www.lgo.org.uk

The Makaton Charity

Information, advice, training and resources to enable people to use the Makaton system of communication.

Tel: 01276 606760
Email: info@makaton.org
www.makaton.org

Mencap

Wide ranging services for people with learning disabilities, their families and carers, including information and advice, training, family support services, housing, jobs and training.

Tel: 0808 808 1111
Email: helpline@mencap.org.uk
www.mencap.org.uk

MERU

Designs and custom-builds specialist equipment for children and young people with disabilities. Also modifies or repairs existing disability equipment.

Tel: 01372 725203
Email: info@meru.org.uk
www.meru.org.uk

Metabolic Support UK

Information, support and advocacy for young people and families affected by inherited metabolic disorders.

Tel: 0800 652 3181
www.metabolicsupportuk.org

Mind

Information, advice, training, local groups and campaigning on behalf of people with mental health needs.

Tel: 0300 123 3393 (information)
Email: info@mind.org.uk
Tel: 0300 466 6463 (legal line)
Email: legal@mind.org.uk
www.mind.org.uk

The Mix

Free, confidential support for under 25s online, via social media, mobile phone. Also offers chat rooms for 11 to 25 year olds.

Tel: (helpline/counselling) 0808 808 4994
Crisis Messenger: text THEMIX to 85258
www.themix.org.uk

Motability see Transport directory.
Muscular Dystrophy UK
Information, advice, research, grants and campaigning on behalf of people with muscle-wasting conditions.
Tel: 0800 652 6352, email: info@musculardystrophyuk.org www.musculardystrophyuk.org

National Autistic Society
Information, advice and resources for people with autism and their families. Offers helplines, an online forum and services directory. Also runs schools and community services.
Tel: 0808 800 4104 www.autism.org.uk

National Careers Service
Information and advice on careers for young people. Offers a CV builder, job hunting tools and webchat.
Tel: 0800 100 900 Textphone: 0800 096 8336 www.nationalcareersservice.direct.gov.uk

National Children’s Bureau (NCB)
Information, advice, training and campaigning on behalf of children, young people and families. Includes information on transition to adulthood.
Tel: 020 7843 6000 www.ncb.org.uk

National Citizen Service
Open to all 15 to 17 year olds to build work and life skills.
Tel: 0800 197 8010 www.ncsyest.co.uk

National Deaf Children’s Society (NDCS)
Information, advice resources and campaigning on behalf of children and young people with hearing impairments.
Tel: 0808 800 8880 Email: helpline@ndcs.org.uk www.ndcs.org.uk www.buzz.org.uk (for young people)

National Eczema Society
Information and advice, resources for schools and healthcare professionals, support groups and research.
Tel: 0800 089 1122 Email: helpline@eczema.org www.eczema.org
NHS Complaints Advocacy

Provides free confidential advice to people with complaints/concerns about the NHS.

Tel: 0300 330 5454
Text: 07960 022939, email: nhscomplaints@voiceability.org
www.nhscomplaintsadvocacy.org

Office of the Public Guardian (OPG)

Protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance.

Tel: 0300 456 0300
Email: customerservices@publicguardian.gsi.gov.uk

Papyrus

Organisation working to prevent suicide in young people aged under 35. Runs HOPELineUK, a phoneline giving support and advice to young people and people worried about a young person’s mental health.

Tel: 0800 068 4141
Text: 07786 209697
Email: pat@papyrus-uk.org
https://papyrus-uk.org

Parliamentary and Health Service Ombudsman

Investigates and makes final decisions on complaints that have not been resolved by the NHS, government departments and other public organisations.

Tel: 0345 015 4033
www.ombudsman.org.uk

Patients’ Association

Free, confidential information and advice about health and social care.

Tel: 020 8423 8999, email: helpline@patients-association.com
www.patients-association.org.uk

PINNT

Information, advice and support groups for patients on Intravenous and Nasogastric Nutrition Therapy and other feeding methods.

Tel: 020 3004 6193
Email: comms@pinnt.com
www.pinnt.com
POhWER

Provides information, advice, support to disabled people and advocates for people who may lack mental capacity, to ensure their views are taken into account.

Tel: 0300 456 2370
Minicom: 0300 456 2364
Email: pohwer@pohwer.net
www.pohwer.net/west-sussex

Reach

Membership-based organisation, providing information and support for children and young people with upper limb differences.

Tel: 0845 130 6225 or 020 3478 0100
Email: reach@reach.org.uk
www.reach.org.uk

Remap

Custom-made equipment designed and built to help disabled people live more independently.

Tel: 01732 760209
Email: data@remap.org.uk
www.remap.org.uk

Rethink Mental Illness

Provides a wide range of services including advice, advocacy, support groups and training for people with mental illness.

Tel: 0300 500 0927
(advice and information) www.rethink.org

Rett UK

Information and advice, clinics for diagnosis of children and adults, local support groups and social activities for families affected by Rett syndrome.

Tel: 01582 798911
Email: support@rettuk.org
www.rettuk.org

Royal National Institute of Blind People (RNIB)

Offers information, advice, training and resources to people with sight loss. Also offers newspapers and magazines in a variety of accessible formats via the RNIB Newsagent.

Tel: 0303 123 9999
Email: helpline@rnib.org.uk
www.rnib.org.uk
www.rnib.org.uk/newsagent
Samaritans see Local Directory

SANE

Information, advice and support for people with mental health needs and their families. Offers a confidential helpline over 16s.

Tel: 0300 304 7000
Email: info@sane.org.uk
www.sane.org.uk

Scope

Wide range of support including information, advice, training, campaigning, local groups and services for disabled people and their families and carers.

Tel: 0808 800 3333
Email: helpline@scope.org.uk
www.scope.org.uk

Sense

Wide range of projects and services for deafblind people (and those with other complex communication needs) and their families. Contact via BSL interpreter as well as the methods below.

Tel/textphone: 0300 330 9256
Email: info@sense.org.uk
www.sense.org.uk

Shine

Specialist information, advice and support for people with spina bifida and hydrocephalus.

Tel: 01733 555988. Email: firstcontact@shinecharity.org.uk
www.shinecharity.org.uk

Shopmobility see Travel Directory

Sibs

Information, advice and local groups for child and adult siblings of disabled people. Separate website for children and young people, with an online forum.

www.sibs.org.uk
www.youngsibs.org.uk

Sickle Cell Society

Information, advice, testing and volunteer support for people and families affected by sickle cell disorders.

Tel: 020 8961 7795
Email: info@sicklecellsociety.org
www.sicklecellsociety.org
Signalong

Resources, training and advice on the Signalong system of communication.

Tel: 01634 727087
Email: admin@signalong.org.uk
www.signalong.org.uk

Skiggle

Network of people willing to give disability-related items to others in times of need. Members can also buy, sell or donate disability aids and equipment via their marketplace.

https://skiggle.co.uk
www.facebook.com/SkiggleUK

Special Needs Jungle

Parent-led information and resources regarding SEND, with articles, latest research, legal advice and support with the EHCP process.

https://specialneedsjungle.com

Steps

Information, advice and support for people affected by lower limb conditions such as talipes (club foot) and hip dysplasia.

Tel: 01925 750271
Email: info@steps-charity.org.uk
www.steps-charity.org.uk

Syndromes without a name (SWAN)

Information, support and an online forum for families of children with undiagnosed genetic conditions.

Tel: 020 7831 0883 (general enquiries)
Email: info@undiagnosed.org.uk
www.undiagnosed.org.uk

Tourettes Action

Charity offering information and support for people with Tourette Syndrome and their families.

Tel: 0300 777 8427
www.tourettes-action.org.uk

Transition Information Network

Website covering transition to adulthood for young people with SEND.

Tel: 020 7843 6000
Email: tin@ncb.org.uk
http://councilfordisabledchildren.org.uk/transition-information-network
Unique (Rare Chromosome Disorder Support Group)

Information and support to families and individuals affected by rare chromosome disorders, and the professionals who work with them.

Tel: 01883 723356
Email: info@rarechromo.org
www.rarechromo.org

Whizz-Kidz

Provides equipment, support and life skills to help disabled young reach their full potential.

Tel: 020 7233 6600
Email: info@whizz-kidz.org.uk
www.whizz-kidz.org.uk

Working Families

Information, advice and campaigning for better work-life balance for UK families.

Tel: 0300 012 0312, email: advice@workingfamilies.org.uk
www.workingfamilies.org.uk

Young Epilepsy

Charity that supports children and young people with epilepsy and associated conditions to develop their full potential.

Tel: 01342 832243 (general enquiries)
Tel: 01342 831342 (helpline)
Email: info@youngepilepsy.org.uk
www.youngepilepsy.org.uk

Young Minds

Mental health information, advice and resources for children and young people.

Tel: 0808 802 5544 (parents’ helpline)
Email: ymenquiries@youngminds.org.uk
www.youngminds.org.uk
Further and higher education directory

SPECIALIST SECONDARY SCHOOLS AND SIXTH FORMS

Fordwater School

Co-educational school for two to 19-year-olds with severe and complex learning difficulties.

Summersdale Road
Chichester, PO19 6PP
Tel: 01243 782475
Email: office@fordwatersch.co.uk
www.fordwatersch.co.uk

Manor Green College

Secondary school for students aged 11 to 19 who have a range of learning difficulties and other complex needs.

Lady Margaret Road, Ifield
Crawley, RH11 0DX
Tel: 01293 520351
Email: office@mgcollege.co.uk
www.manorgreen-college.w-sussex.sch.uk/web

Oak Grove College

A secondary school providing special education for students aged 11 to 16 who have learning difficulties.

The Boulevard
Worthing, BN13 1JX
Tel: 01903 708870, email: office@oakgrovecolleage.org.uk
www.oakgrovecollege.org.uk

Queen Elizabeth II Silver Jubilee School (QEII)

School for two to 19 year olds with severe or profound and multiple learning difficulties and other complex needs.

Comptons Lane
Horsham, RH13 5NW
Tel: 01403 266215
Email: office@qe2school.co.uk
www.queenelizabeth2.w-sussex.sch.uk

Woodlands Meed College

For young people aged 14 to 19 with a range of special educational needs.

Birchwood Grove Road
Burgess Hill, RH15 0DP
Tel: 01444 244133, email: office@woodlandsmeed.co.uk
www.woodlandsmeed.co.uk

INDEPENDENT SPECIALIST SIXTH FORMS

Chailey Heritage School
(out of county)

A charitable special school for children aged three to 19 years with complex physical disabilities, high health needs, visual and hearing impairments and associated learning difficulties.
Farney Close School

A mixed residential special school for 9 to 18 year olds with social, emotional and behavioural difficulties, Asperger’s, Tourette Syndrome, moderate learning difficulties, dyslexia or moderate speech and language difficulties.

Bolney Court, Crossways, Bolney Haywards Heath, RH17 5RD
Tel: 01444 881811
www.farneyclose.co.uk

Ingfield Manor School

A day and weekly boarding school for children aged three to 19 years with cerebral palsy or physical difficulties.

Ingfield Manor Drive, Five Oaks, Billingshurst, RH14 9AX
Tel: 01403 782294, email: ingfield.manor@ambitoeducation.co.uk
www.ingfieldmanorschool.co.uk

Muntham House School

Day/residential school for boys aged eight to 18 years with emotional, social and mental health difficulties, including challenging behaviour, autism and ADHD.

Barns Green, Horsham, RH13 0NJ
Tel: 01403 730302
Email: office@muntham.org.uk
www.muntham.org.uk

Philpots Manor School

Day/residential education for children aged seven to 19 with a range of social, emotional, behavioural and mental health needs or social communication difficulties.

West Hoathly, East Grinstead, RH19 4PR
Tel: 01342 810268, email: info@philpotsmanorschool.co.uk
www.philpotsmanorschool.co.uk

Springboard Education

Education for children aged 11 to 19 with social, emotional and behavioural difficulties, attention deficit disorders or Asperger’s.

55 South Street
Lancing, BN15 8AN
Tel: 01903 605980, email: senior@springboardeducation.co.uk
www.springboardeducation.co.uk
MAINSTREAM SCHOOLS WITH SIXTH FORMS IN WEST SUSSEX

The Angmering School

Station Road
Angmering, BN16 4HH
Tel: 01903 772351, email: office@theangmeringschool.co.uk
www.angmeringschool.co.uk

Bishop Luffa School

Westgate
Chichester, PO19 3HP
Tel: 01243 787741
www.bishopluffa.org.uk

Chichester High School

Kingsham Road
Chichester, PO19 8EB
Tel: 01243 787014
Email: office@chs-tkat.org
www.chs-tkat.org

Felpham Community College

Felpham Way, Felpham
Bognor Regis, PO22 8EL
Tel: 01243 826511
Email: fcc@felpham.org.uk
www.felpham.com

Hazelwick School

Three Bridges
Crawley, RH10 1SX
Tel: 01293 403344
Email: office@hazelwick.org.uk
www.hazelwick.org

The Holy Trinity Church of England Secondary School

Buckswood Drive, Gossops Green
Crawley, RH11 8JE
Tel: 01293 423690, email: office@holytrinity.w-sussex.sch.uk
www.holytrinity.w-sussex.sch.uk

Ifield Community College

Crawley Avenue, Crawley, RH11 0DB
Tel: 01293 420500
Email: office@ifieldcc.co.uk
www.ifieldcc.w-sussex.sch.uk

Imberhorne School

Imberhorne Lane
East Grinstead, RH19 1QY
Tel: 01342 310986
Email: sixthform@imberhorne.co.uk
www.imberhorne.co.uk
The Littlehampton Academy
Fitzalan Road
Littlehampton, BN17 6FE
Tel: 01903 711120
Email: office@tla.woodard.co.uk
www.tla.woodard.co.uk

Midhurst Rother College
North Street
Midhurst, GU29 9DT
Tel: 01730 812451, email:
Sarah.banbury@mrc-academy.org
www.mrc-academy.org

Oriel High School
Maidenbower Lane, Maidenbower,
Crawley, RH10 7XW
Tel: 01293 880350
Email: office@oriel.w-sussex.sch.uk
www.oriel.w-sussex.sch.uk

The Regis School
Westloats Lane
Bognor Regis, PO21 5LH
Tel: 01243 871010, email:
enquiries@theregisschool.co.uk
www.theregisschool.co.uk

Sackville School
Lewes Road
East Grinstead, RH19 3TY
Tel: 01342 410140, email:
secretary@sackvilleschool.org.uk
www.sackville.w-sussex.sch.uk

Shoreham Academy
Kingston Lane
Shoreham-by-Sea, BN43 6YT
Tel: 01273 274100, email:
enquiries@shoreham-academy.org
www.shoreham-academy.org

Sir Robert Woodard Academy
Upper Boundstone Lane, Sompting,
Lancing, BN15 9QZ
Tel: 01903 767434, email:
enquiries@srwa.woodard.co.uk
www.srwa.woodard.co.uk

Steyning Grammar School
Has a special needs team supporting pupils with learning, behaviour and physical difficulties.

Shooting Field
Steyning, BN44 3RX
Tel: 01903 814555 or for Sixth Form College: 01903 810526
Email: sgs@sgs.uk.net
www.sgs.uk.net

St Wilfrid’s Catholic School
St Wilfrid’s Way, Old Horsham Road
Crawley, RH11 8PG
Tel: 01293 421421
Email: office@stwilfrids.com
www.stwilfrids.com
Thomas Bennett Community College
Ashdown Drive, Crawley, West Sussex, RH10 5AD
Tel: 01293 526255, email: admin@thomasbennett-tkat.org
www.thomasbennett-tkat.org

The Weald Community School and Sixth Form
Station Road
Billingshurst, RH14 9RY
Tel: 01403 787200 (main school)
Tel: 01403 787283 (sixth form)
Email: office@theweald.org.uk
www.theweald.org.uk

MAINSTREAM SIXTH FORM COLLEGES

College of Richard Collyer
Hurst Road
Horsham, RH12 2EJ
Tel: 01403 210822
Email: admin@collyers.ac.uk
www.collyers.ac.uk

OTHER OPTIONS

Asphaleia Training
Runs provision for young people aged 14 to 25 who may find mainstream education a struggle.
Tel: 01903 823546
Email: headoffice@asphaleia.co.uk
www.asphaleia.co.uk

East Clayton Farm
Offers alternative provision for young people primarily at risk from permanent school exclusion.
Tel: 01903 741011
Email: info@lorica.org.uk
www.eastclaytonfarm.org.uk

West Sussex Alternative Provision College (WSAPC)
For young people (up to year 11 only) who have been permanently excluded, are at risk of exclusion or cannot attend school for medical reasons. Centres located across the county – see website for more information.
Tel: 0330 222 5209, email: fairaccess@westsussex.gov.uk
http://apcollege.co.uk

FE COLLEGES

Chichester College (including Brinsbury Campus, Pulborough)
Westgate Fields
Chichester, PO19 1SB
Tel: 01243 786321
Email: info@chichester.ac.uk
www.chichester.ac.uk
Crawley College
(including Horsham Training Centre)

College Road
Crawley, RH10 1NR
Tel: 01293 442213
Email: info@crawley.ac.uk
www.crawley.ac.uk

Northbrook Metropolitan College

Campuses in Worthing and Shoreham

Tel: 0845 155 6060, email:
enquiries-worthing@gbmc.ac.uk
www.northbrook.ac.uk

Plumpton College (out of county)

Offers practical courses including horticulture, floristry and landscaping.
Also offers apprenticeships and supported internships.

Ditchling Road, Plumpton
East Sussex, BN7 3AE
Tel: 01273 890454
www.plumpton.ac.uk

Worthing College

1 Sanditon Way
Worthing, BN14 9FD
Tel: 01903 275755
Email: info@worthing.ac.uk
www.worthing.ac.uk

LOCAL UNIVERSITIES

University of Brighton

Mithras House, Lewes Road
Brighton, BN2 4AT
Tel: 01273 644644 (admissions)
Email: admissions@brighton.ac.uk
www.brighton.ac.uk

University of Chichester

College Lane
Chichester, PO19 6PE
Tel: 01243 816000
Email: admissions@chi.ac.uk
www.chi.ac.uk

University of Sussex

Sussex House, Falmer
Brighton, BN1 9RH
Tel: 01273 606755
Email: study@sussex.ac.uk
www.sussex.ac.uk

EDUCATIONAL ORGANISATIONS

ACE Education Advice

Provides free, confidential information, advice and support to parents across a range of issues including special educational needs.

Tel: 0300 011 5142 (advice line)
Email: enquiries@ace-ed.org.uk
(general enquiries)
www.ace-ed.org.uk
Alliance for Inclusive Education (ALLFIE)

National network of disabled people, parents and teachers campaigning for inclusive education.

Tel: 020 7737 6030
Email: info@allfie.org.uk
www.allfie.org.uk

Autism and Social Communication Team (WSCC)

A team of specialists with expertise in autism who aim to promote the educational, social and emotional development of children/young people; working with their parents and educational settings. Referrals should be made via schools.

Tel: 0330 222 8525, email: helen.cottell@westsussex.gov.uk
https://westsussex.local-offer.org/services/114

Centre for Studies on Inclusive Education (CSIE)

Lobbying, campaigning, research and training for inclusive education.

Tel: 0117 353 3150
Email: admin@csie.org.uk
www.csie.org.uk

ClearVision

Postal lending library of mainstream children’s books with braille and printed text, and tactile books.

Tel: 020 8789 9575
Email: info@clearvisionproject.org
www.clearvisionproject.org

Disabled Students’ Allowances see Student Finance England.

Down Syndrome Education International

Information, advice and research to improve education and outcomes for young people with Down syndrome.

Tel: 0330 043 0025
Email: hello@dseinternational.org
www.dseinternational.org/en-gb

Educational Psychology Service (WSCC)

Works with children, young people, parents and schools using psychology to improve learning and development. It provides advice to the Local Authority (LA) to support assessments of children's SEND. For general enquiries call the number below.
Ethnic Minority and Traveller Achievement Service

Works with schools and families to raise the attainments of children from black, Asian, Roma, Traveller and other ethnic minorities.

Black, Asian and ethnic minority service
Tel: 0330 222 2111
Email: emat@westsussex.gov.uk

Traveller service
Tel: 0330 222 2155
Email: tes@westsussex.gov.uk
http://schools.westsussex.gov.uk/Services/3381

First-tier Tribunal, see SENDIST

Global Mediation

If you disagree with the Local Authority over EHC assessment, the provision of or content of an EHC Plan, you have the right to go to mediation, or to appeal to the First-tier Tribunal. In order to register an appeal to the tribunal, you must first contact an independent mediation adviser and obtain a certificate to prove that you have done so.

Tel: 0800 064 4488
Email: info@globalmediation.co.uk
www.globalmediation.co.uk

Independent Parental Special Education Advice (IPSEA)

Independent advice on education matters for families of children with SEND. Also provides training on the SEND legal framework to help parents and professionals, an advice service and a tribunal advice service. Book a call back if needed on their website.

www.ipsea.org.uk

Learning and Behaviour Advisory Team (LBAT) (WSCC)

Supports young people up to the age of 16, their families and schools where learning and/or behaviour difficulties are affecting the young person’s progress in school.

Email:
helen.cottell@westsussex.gov.uk
https://westsussex.local-offer.org/services/229
Listening Books
Postal and internet-based library service providing audio books for people who find it difficult or impossible to read owing to illness, learning difficulties or disabilities.
Tel: 020 7407 9417
Email: info@listening-books.org.uk
www.listening-books.org.uk

NASEN
Promotes the education, training, and development of all those with special educational and additional learning support needs.
Tel: 01827 311500
Email: welcome@nasen.org.uk
www.nasen.org.uk

National Union of Students (NUS)
Represents the interests of students. Every university and most colleges have a student union affiliated to the NUS, which provides support to students and information and advice for prospective students.
Tel: 0845 521 0262
www.nus.org.uk
www.facebook.com/nationalunionofstudents

Natspec
Online directory of organisations offering specialist further education and training for students with learning difficulties and/or disabilities.
Tel: 0115 854 1322
Email: info@natspec.org.uk
www.natspec.org.uk

The National Careers Service
Information and advice about education, training and work. Webchat or email form available on website.
Tel helpline: 0800 100 900
Text messages: 07766 413219
Textphone: 08000 968336
www.nationalcareersservice.direct.gov.uk

Network 81
Information, advice, training and befriending to parents on issues around special educational needs.
Tel: 0845 077 4055
Email: advice@network81.org.uk
www.network81.org.uk
NICE

Workshops, training and outreach services on principles and methods of conductive education for people with movement disorders such as global development delay, dyspraxia, cerebral palsy and acquired brain injury.

Tel: 0121 449 1569
Email: foundation@conductive-education.org.uk
www.conductive-education.org.uk

Ofsted (Office for Standards in Education, Children’s Services and Skills)

Government body that regulates and inspects schools and children’s services.

Tel: 0300 123 1231
Email: enquiries@ofsted.gov.uk
www.gov.uk/government/organisations/ofsted

Pupil Entitlement

Works with schools and families to ensure high levels of school attendance. Also offers advice and support to parents who home-educate.

Tel: 0330 222 8200
http://schools.westsussex.gov.uk/Services/3328

SENDIST (Special Educational Needs and Disability Tribunal) also known as First-Tier Tribunal

Tribunal that hears appeals by parents against decisions made by their local education authority concerning their child’s education.

Tel: 01325 289350, email: sendistqueries@hmcts.gsi.gov.uk

Sensory Support Team

Provision of services to children and young people aged 0 to 19 years who have hearing, visual or multi-sensory needs.

Tel: 01903 270430, email: sensory.support@westsussex.gov.uk

Student Bursary Support Service

Online service used to administer student support for the Care to Learn scheme and the 16 to 19 Bursary Fund for vulnerable students.

www.gov.uk/guidance/student-bursary-support-service
Student Finance England

Government website with details of funding that students are entitled to, including Disabled Students’ Allowance.

Tel: 0300 100 0607
Textphone: 0300 100 0622
www.gov.uk/student-finance/extra-help

University and College Admission Service (UCAS)

Central organisation that processes university applications. Can support young people making post-GCSE choices and those applying for undergraduate/postgraduate courses.

Tel: 0371 468 2568 (year 11 students)
Tel: 0371 468 0468 (undergraduates)
www.ucas.com

SEND HUB NETWORKS

SEND Hub Networks enable schools and other organisations to share expertise locally and access support for young people with SEND aged 0 to 25. If you feel your child needs additional educational support speak to your child’s school to see what your local SEND Hub Network can offer.

Billingshurst, Pulborough and surrounding areas (Weald SEND Alliance)

Email: SendAlliance17@gmail.com
http://wealdsendalliance.org.uk

Burgess Hill and surrounding areas (Meeds SEND Alliance)

Tel: 01444 244133, email: sendalliance@woodlandsmeed.co.uk
www.woodlandsmeed.co.uk

Chichester, Bognor and surrounding areas (NOVIO)

www.noviosupport.org

Horsham (Compass@QEII)

Tel: 01403 266215
Email: compass@queenelizabeth2.w-sussex.sch.uk
www.queenelizabeth2.w-sussex.sch.uk/website/compass__qeii

Littlehampton and surrounding areas (SHELL)

www.shellhub.org

Midhurst, Petworth and surrounding areas (Rother Valley Inclusion)

Email: enquiries@rvhub.org.uk
www.rvhub.org.uk
Travel directory

The Aldingbourne Trust
Can help disabled people to plan travel, apply for discount schemes and book tickets.
www.aldingbournetrust.co.uk

Blue Badge Scheme (WSCC)
Tel: 01243 777653, email: blue.badges@westsussex.gov.uk
www.westsussex.gov.uk/bluebadge

Bus companies

Community Transport
Various Community Transport Service providers operate in West Sussex. They can help people who find it difficult to use public transport.
www.westsussex.gov.uk/communitytransport

Disabled Go
Website with information on accessible places across the UK, including shops, restaurants and train stations.
Tel: 01438 842710
Email: enquiries@disabledgo.com
www.disabledgo.com

Disabled Person’s Bus Pass
Issued by West Sussex County Council.
Tel: 0330 222 6222
Email: buspass@westsussex.gov.uk

Disabled Person’s Railcard
Offers adults with disabilities a third off most fares across the UK. If you’re travelling with a carer they will also get a third off their rail fare.
Tel: 0345 605 0525
Minicom/Textphone: 0345 601 0132
Email: disability@raildeliverygroup.org
www.disabledpersons-railcard.co.uk

Helping Hand Scheme
A simple card that the holder can pass to a bus driver to give them extra information such as ‘can you call out the correct stop’ or ‘needs priority seating’.
Tel: 01273 886200
www.metrobus.co.uk/helping-hand-scheme
**Motability**

National scheme enabling people to exchange the Higher Rate Mobility component of Disability Living Allowance (DLA) or the Enhanced Rate Mobility component of Personal Independence Payment (PIP) for a car, powered wheelchair, or scooter.

Tel: 0300 456 4566
Minicom/Textphone: 0300 037 0100
www.motability.co.uk

**National Express Disabled Coachcard**

Offers a third off travel on National Express coaches throughout the UK.

Tel: 0871 781 8181
Tel: 0371 781 8181 (assistance)
www.nationalexpress.com/en/offers/coachcards/disabled

**National 16-25 Railcard**

Railcard offering 16 to 25 year olds a third off rail fares. Mature students in full-time education can also apply.

Tel: 0345 300 0250, email: railcardhelp@railcards-online.co.uk
www.16-25railcard.co.uk

**Pass Plus**

A six-hour course designed to help new drivers to improve their skills behind the wheel.

www.gov.uk/pass-plus

**The Rough Guide to Accessible Britain**

Online guide with reviews and information on disabled access at attractions around the UK.

www.accessibleguide.co.uk

**Shopmobility**

National federation of wheelchair, scooter and mobility providers.

Tel: 01933 229644 (central enquiries)
Email: shopmobility@bhta.com
www.nfsuk.org

Bognor Tel: 01243 830077
www.bognorshopmobility.co.uk

Chichester Tel: 07932 802778
www.cfirst.org.uk – search for ‘Chichester’

Horsham Tel: 01403 249015
www.horsham.gov.uk – search for ‘shopmobility’
Littlehampton Tel: 01903 733004
www.shopmob1.plus.com

Worthing Tel: 01903 820980
www.worthingtowncentre.co.uk – search for ‘shopmobility’

Sussex Student Card
Discount season ticket scheme with up to a third off rail tickets from home to school or college for 16 to 19 year olds.
www.westsussex.gov.uk/studentcard

Taxi vouchers (Mid Sussex)
Tel: 01444 477450, email: taxivouchers@midsussex.gov.uk
www.midsussex.gov.uk/travel

Tourism for All
Information and advice that enables disabled people to participate in travel and leisure.
Tel: 0845 124 9971
Email: info@tourismforall.org.uk
www.tourismforall.org.uk

Transport to College
Provides transport to college for young people who are entitled due to the distance, type of course and their needs.
Tel: 0330 222 3588, email: Post16Transport@westsussex.gov.uk
www.westsussex.gov.uk/schooltransport

Unizone
Season ticket scheme giving discounted unlimited travel to college and university students within specific Unizone areas.
www.southernrailway.com/tickets/discounts-and-railcards/unizone

Your Space, West Sussex
Has information on travel schemes and discounts.
www.westsussex.gov.uk/education-children-and-families/your-space/leisure

JOURNEY PLANNING

Local travel
www.travelinesoutheast.org.uk

Cycle route planner
Travel around London
www.tfl.gov.uk

National travel
www.traveline.info

National Rail Enquiries
Tel: 0345 748 4950
Textphone: 0345 605 0600
www.nationalrail.co.uk

National Express Assisted Travel Service
Tel: 0371 781 8181
Email: addl@nationalexpress.com
Reaching Families  * Transition Planning  * EHC Needs Assessment  * EHC Plan  * Raising the Participation Age  
* Shared Lives  * Personalised Independence Payment  
* Apprenticeship  * BTec  * Person-centred planning  
* Direct Payments  * Advocacy  * Inclusion  * Bursary  
* Disabled Student’s Allowance  * Needs Assessment  
* Blue Badge  * Personalisation  * Assistive Technology  
* Equality Act  * Personal Assistant  * Motability  
* Supported Internship  * Senior Planning Co-ordinator  
* Passported benefits  * Respite  * Adult CarePoint  
* Supported Housing  * Disabled Facilities Grant  * SENDIAS  
* Accessible Housing  * Further Education  * Occupational Therapist  * Shopmobility  * Higher Education  
* Year 9 Transition Review  * Personal Budget  * Sensory Needs Service  
* Circle of Support  * Young Carers  
* Needs Assessment  * Mental Capacity  * NVQ  
* Educational Psychologist  * PALS  * DLA  * Local Offer  
* Employment Support Allowance  * Student Union  
* Appointee  * Buddy scheme  * Carer’s Assessment  
* Disabled Facilities Grant  * Universal Credit  
* Specialist Provision  * Discrimination by Association  
* Community Equipment  * Inclusion  * Parent Carer  
* Personalisation  * Vocational Qualification  
* Legacy Benefits  * Co-production  

* Jargon Buster **
Introduction

This jargon buster is a collection of words used in transition by health, social services and education – words, acronyms and phrases we come across every day. The jargon buster is not comprehensive. That would be all but impossible, but we hope that the words and terms we have included are the ones most relevant to parents and families.

If you would like to comment on our jargon buster or suggest other words and phrases we should include please contact our Project Manager, Brian O’Hagan, at: info@reachingfamilies.org.uk.

Accessible Housing – homes that have been adapted for example, they may have ramped access, handrails, widened doors, raised electrical sockets, a wet room and other things that make them suitable for a disabled person.

Access to Work – a grant to enable disabled people to work, including financial help to you or your employer. Support can include help with transport costs, equipment needed for the workplace, a communicator at interviews or a support worker to help disabled people at work.

Adults’ CarePoint – your initial point of contact to speak to social care about support for adults in West Sussex. If you feel your young person needs support from social care, or that you do as their carer, make initial enquiries through the CarePoint.

Advice – term to describe reports provided by both parents and professionals as part of the process of Education Health and Care Needs Assessment (see below).

Advocacy – independent support representing and acting on behalf of an individual, family or group. Often used to support people with learning disabilities.

Annual Review – yearly meeting between teachers, parents and young people with Education Health and Care Plans (EHC Plans) to review the young person’s progress.

Appointee – a parent, friend or professional who acts on behalf of someone to help with matters such as claiming Personal Independence Payment (PIP), for example.
**Apprenticeship** – work-based schemes where a young person (apprentice) works alongside experienced staff to gain job-specific skills lead to vocational qualifications. Open to over 16s who are not in full-time education.

**Blue Badge** – parking permit that allows people with severe mobility problems to park nearer to where they need to go.

**BTEC** – a vocational qualification, often studied by 16 to 19 year olds.

**Buddy Scheme** – pairs up people with and without disabilities so that a disabled young person can have peer support and increase their independence.

**Bursary** – an amount of money given to a person to help them to study.

**CAMHS (Children and Adolescent Mental Health Service)** – mental health support for children, young people under 18 and their families. In West Sussex the service is provided by Sussex Partnership NHS Foundation Trust.

**Care Package** – the services and support provided following assessment by social services.

**Carer’s Allowance** – a taxable benefit for someone over 16 who spends at least 35 hours per week caring for a disabled person and earns less than £120 per week (after taxes and expenses).

**Carer’s Assessment** – an evaluation of a carer’s needs carried out by social care services in order to decide what help is needed and available.

**CBT (Cognitive Behavioural Therapy)** – term used to describe a number of therapies that involve trying to change the way a person thinks and behaves. Often used in treating depression, anxiety disorders, low self-esteem and/or behavioural problems.

**Child Tax Credits** – see Legacy Benefits.

**Children’s Community Nursing Team** – trained nurses who provide care to children and young people up to the age of 18 outside of hospital.

**Circle of Support** – informal group of people (usually family and friends) who meet together on a regular basis to help somebody accomplish their personal goals in life. Sometimes used in supporting people with learning disabilities.
Clinical Child Psychologist – a healthcare professional who diagnoses, assesses and treats children and young people with behavioural problems, depression, personality disorders.

Co-production – an approach to working when all team members agree outcomes, recommendations, plans, actions and materials. It builds on participation and assumes effective consultation and information sharing.

Differentiation – an approach to teaching that recognises that all students learn at different rates and in different ways and are accommodated in the classroom to ensure they have the best possible chance of learning.

Direct Payments – see Personal Budgets. You can opt to receive your Personal Budget as a payment to you (or a person you nominate) so that you can choose and arrange your own care and support services.

Disability Equality Duty – a legal requirement of all public bodies to promote equality for disabled people. Also requires public bodies to issue a Disability Equality Scheme which sets out how disabled people have been involved in developing the scheme, what improvements will be made to policy and service delivery and how information will be collected to demonstrate how the public body in question has met its targets.

Disabled Facilities Grant – local council grant towards the cost of adapting a home for someone who is disabled.

Disabled Students’ Allowance – a grant to help students with extra costs occurring as a direct result of a disability, ongoing health condition, mental health condition or specific learning difficulty.

Disapplication – removal or lifting of any element of the National Curriculum for a child with special educational needs and disabilities.

Discrimination by Association – practice of discriminating against someone because of their links with someone else, for example, employment discrimination against someone with caring responsibilities. Protection against discrimination by association was included in the Equality Act 2010.
DLA (Disability Living Allowance) – tax-free benefit for disabled children under 16 who need help with personal care and/or mobility.

Education Supervision Order – legal provision enabling the local education authority to supervise a child not receiving proper education, to ensure they receive sufficient full-time education; and their parents get advice and support.

Educational Psychologist – professional responsible for addressing problems encountered by children and young people that hinder their learning and participation in school and other activities. Works in a variety of ways including observations, interviews and assessments, and offers consultation, advice and support to teachers and parents.

EHC Needs Assessment – the process by which children and young people with special educational needs and disabilities are assessed for an Education, Health and Care Plan.

EHC Plan (Education, Health and Care Plan) – for children and young people aged up to 25 who need more help in school or college than is normally available through standard special educational needs support. The plan should be drawn up by the local authority in co-production with the young person, their parents and relevant education, health and social care professionals.

Equality Act (2010) – legislation that improves the civil rights of disabled people in relation to education, employment, accessing goods and services, and for disabled people who rent property and wish to make improvements to their home. Also requires all public bodies to actively promote equality of opportunity for disabled people.

First-tier Tribunal – see SENDIST

Further Education (FE) – learning for young people between the ages of 16 and 19. It includes school sixth forms, sixth form colleges and further education (FE) colleges.

Higher Education (HE) – learning provided by universities and similar institutions that offer degrees and Higher National Diplomas (HNDs).

Inclusion – commonly used term in education to describe the principle by which children with special educational needs and disabilities attend school and participate in the curriculum alongside other pupils.
Inclusion Coordinator – another name used to describe the role of the SENDCo (Special Educational Needs and Disabilities Coordinator).

Key Stages – the National Curriculum is broken down into four phases known as key stages. They are based on age groups: Key Stage 1 (5-7); Key Stage 2 (7-11); Key Stage 3 (11-14); Key Stage 4 (14-16).

Key Worker – health or social care professional who acts as a point of contact and source of information and support to children, parents and families. Sometimes known as a Lead Professional.

Legacy Benefit – Universal Credit is an integrated means-tested benefit for people in or out of work. It is replacing: Child Tax Credits; Employment and Support Allowance (ESA); Housing Benefit; Income Support; Job Seeker’s Allowance (JSA); Working Tax Credits, which are now called ‘legacy benefits’.

Local Offer – see page 4.

LSA (Learning Support Assistant) – widely used term to describe a member of school staff who provides individual or small group support in the classroom to children with special educational needs and disabilities.

Mainstream School – ordinary or community school managed by the local authority.

Mediation – a service commissioned by local authorities designed to help settle disagreements between parents or young people and local authorities over EHC Needs Assessments and Plans before considering tribunal.

Mental Capacity – if someone has ‘mental capacity’, they’ve the right to make their own decisions, whether others agree with those choices or not. This right is protected by law by the Mental Capacity Act 2005.

Modification – alteration to a programme of study or activity designed to give students better access to that element of the curriculum.

Multi-disciplinary – a group of professionals who assess and plan support for a child or adult.

National Curriculum – covers the learning of all children aged five to 16 years in state schools in England. Includes the subjects children should learn, the knowledge, skills and understanding children should have in each subject and targets to measure progress.
**Needs Assessment** – process carried out by social workers to identify both a child’s and their family’s needs, and their eligibility for support from social care services.

**Network 81** – provides support, advice and training around education for families of children with Special Educational Needs and Disabilities.

**NVQ (National Vocational Qualifications)** – can be studied by people in employment, or by school and college students who are on a work placement or working part-time.

**OFSTED (Office for Standards in Education, Children’s Services and Skills)** – regulates and inspects childcare and educational services. Provides online reports on childcare providers and schools.

**PALS (Patient Advice and Liaison Service)** – provides information on the NHS and investigates complaints made by patients.

**Parent Carer** – term used to describe and recognise the dual roles of parents of children with special needs and disabilities who have caring responsibilities above and beyond other parents.

**Passported benefits** – benefits you can get if your child receives DLA. They include Carer’s Allowance, extra payments to top up earned income, and top ups on your own benefits such as Universal Credit.

**Pastoral Care** – provision by schools that focuses on the personal, social and emotional needs of pupils.

**Pastoral Support Plan** – school strategy to help children and young people improve their social, emotional and behavioural skills. Often used with children at risk of exclusion.

**Personal Assistant (PA)** – someone who provides paid support and care to disabled children and adults. They may offer support with every day activities such as shopping, leisure activities, washing and personal care.

**Personal Budgets** – an agreed amount of money that is allocated to a disabled person by their local council following an assessment of care and support needs, so that he or she can control the money and choose their care and support.

**Personalisation** – the provision of tailored care and support to people based on their individual needs and
the choices they make about how they want to live their lives.

**Person-centred Planning** – approach in which people with SEND and their families are equal partners with professionals when planning out their life and the support they need to achieve specific outcomes.

**PIP (Personal Independence Payment)** – a government benefit for people aged 16 and over. Intended to help with some of the extra costs caused by a long-term health condition or disability.

**Provision Map** – a brief document giving a view of how a school will support a child with additional needs.

**Psychiatrist** – medically qualified doctor who specialises in the diagnosis, treatment and prevention of mental health conditions.

**Raising the Participation Age** – legislation that means young people are expected to stay in some form of education or training until their 18th birthday.

**Re-consideration** – the re-assessment of applications for PIP or DLA that were initially turned down. Many decisions are overturned on reconsideration.

**Respite** – a break from caring for someone with an illness or disability.

**Revision** – a review of PIP/ DLA applications where the person disagrees with the rate at which they have been assessed. If your application for a revision is successful, the revision takes effect from when the original decision was made, which means payments can be backdated.

**SENAT (SEN Assessment Team)** – the local authority team responsible for doing EHC Needs Assessments and co-producing an EHC Plan with parents and professionals, if it is decided that a plan is required.

**SENDCo (Special Educational Needs and Disabilities Coordinator)** – member of staff responsible for the co-ordination of special educational needs provision in schools.

**SEND Code of Practice** – statutory Government guidance for organisations that work with and support children and young people with special educational needs and disabilities. Covers issues like the Local Offer, assessments, EHC Plans, annual reviews, inclusion, and preparing for adulthood, for example.
SEND IAS (Special Educational Needs and Disability Information, Advice and Support Service) – impartial provider of information and advice to children and young people with SEND and their parents about matters relating to their SEND, including EHC Plans, assessments, annual review, appeals and tribunals.

SENDIST (Special Educational Needs and Disability Tribunal) – an independent body that hears appeals against decisions made by local authorities on EHC Assessments, EHC Plans and Statements of SEN. Also known as the First-tier Tribunal.

Senior planning Coordinator – a key professional from the Local Authority involved in transition planning for your child. They should be invited to the Year 11 annual review and also the Year 12 and 13 reviews if your young person is leaving school or college. They may also stay involved when the young person leaves school to attend further education or training.

Shopmobility – scheme that operates in many city centres and shopping centres where a disabled person can borrow a wheelchair or scooter.

Short break – fun, leisure and social activities for children and young people with SEND outside the school day, which also give parents and carers a break from their caring role.

Specialist Provision – a setting which is organised to make special educational provision for pupils with Special Educational Needs and Disabilities whose needs cannot be met in a mainstream setting.

Statutory Assessment – now known as an EHC Needs Assessment, the process by which local authorities carry out an assessment of a child’s special educational needs. A number of people participate in the process including: parents; the child’s school or college; an educational psychologist; health care professionals; and social care services. At the end of the process the local authority will either issue an EHC Plan (see above) or explain why one is not necessary and how the child’s needs will be met.

Student Union (SU) – all universities and most colleges have an SU that’s affiliated to the National Union of Students (NUS). Provides welfare services and can be a useful source of information and support when applying to a university, or when you have been offered a place.
Supercession – a review of PIP/ DLA (see above) where the person’s circumstances have changed and they believe they need more help.

Supported Internship – a structured study programme based primarily with an employer, which aim to help young people who have an EHC Plan to achieve paid employment through learning in the workplace. Internships are unpaid, and last for a minimum of six months.

Supported living – generally means living in accommodation where there are staff on site, either in a ‘group’ home, where people have their own room but share other facilities; or a self-contained flat or studio. It focuses on helping the young person to develop their life skills and independence, as well as learning to share the responsibility for cooking, cleaning and shopping.

Temporary Disapplication – removal of those parts of the National Curriculum where it is impossible or inappropriate for the child to participate.

Transition Planning – the holistic approach to working out what a young person will need to support them as they head towards adulthood to ensure that they can live as independently as possible. Covers all aspects including further education and employment to health and social care, where they will live and how they can play an active role in their local community.

Universal Credit – a monthly benefit payment which is rolling out across the country and replaces: Child Tax Credits; Housing Benefit; Income Support; Income-based Job Seeker’s Allowance; income-related Employment and Support Allowance; and Working Tax Credits (see Legacy Benefits).

Will Trusts – a formal legal arrangement set up as part of a will where the beneficiary is a vulnerable disabled person to protect people who may not have the capacity to manage their own finances. There are several types of trust, including Discretionary Trusts and Disabled Person’s Trusts (DPT). To qualify for a DPT, your child will need to meet certain conditions, such as receiving the middle or higher rate care component of DLA, or receiving PIP.

Work Capability Assessment – an assessment carried out by a healthcare professional of a person’s capability for work or ‘work related activity’. Can include a medical assessment.
Working Tax Credit – see Legacy Benefits.

Year 9 Transition Review – a key review where you and your child will be asked to think about their future and, with the input of the professionals involved with your child, start to plan out what your child would like to do after the age of 16 and how they will be supported to make it happen.

Young carer – a young carer is someone aged 18 or under who helps look after a relative who has a condition, such as a disability. For example, siblings of a disabled young person may have to take on household chores, or help with some care tasks. Young carers can have their needs assessed by social care, too.
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