Making Sense of it All

A guide for parents of children aged 0 to 14 years with special needs and disabilities in West Sussex

Third edition

September 2017
About Reaching Families

Reaching Families was established in 2008 by parent carers to ‘empower, care for and inform parents and families of children with special educational needs and disabilities 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 SEND aged 0 to 14 in West Sussex.
• Making Sense of Adult Life – a transition guide for parents of young people aged 14+ with SEND in West Sussex.
• 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 wide range of training workshops at various locations and venues across West Sussex for parents of children and young people with SEND aged from birth to 25 years.
• Umbrellas – we run several support groups for parent carers of children who attend mainstream schools – please refer to our website or Facebook page for further details.
• Our Facebook group – this rapidly growing forum is one of the most popular groups for West Sussex parent carers. As well as staying up-to-date with local events, members can chat to other parents in similar situations and share advice and experiences.

Editor’s note: In order to be as inclusive as possible and to avoid unnecessary repetition, in this book we have used ‘SEND’ – Special Educational Needs and Disabilities – as an umbrella term to cover any condition or need that children may have. For information on specific disabilities such as autism, cerebral palsy and Down syndrome, please refer to our fact sheets, which can be downloaded from our website at: www.reachingfamilies.org.uk/factsheets.htm.
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As head teacher at QEII School I have had the privilege to work with many extraordinary young people and their families, all of whom have been inspirational and have never failed to impress me with their resilience and determination as they progress through their very individual and often extremely challenging journeys from birth to adulthood.

When I started on my journey at QEII in the early 1990s there was little to support our families and I recall some extremely harrowing meetings where we struggled to find any support or even a way to point our families in the right direction.

When I look at what is available for families now, I realise just how far we have come and this is due to the tireless commitment of many innovative and dedicated individuals who have worked so hard, mostly in a voluntary capacity, to create a wide range of support networks and resources. For me, *Making Sense of it All* is one of the most important and valuable resources available to our families and to the wide range of professionals in our region. I am so pleased that I have been able to provide our families with copies of this amazing book, which has been an absolute lifeline for so many families.

Reaching Families was established by parent carers to ‘empower, inform and care for parents and families of children with special needs in West Sussex’ and they do that so successfully. *Making Sense of it All* was first published in 2012 and is an absolute must for families at any stage of their journey caring for children and young people with special needs and disabilities.
The book provides a wealth of information and advice that has been researched and written for parents and carers by parents and carers. When I ask my families what has helped them the most they all reply; advice from parents and carers who have trod a similar path and can share their experiences. One parent told me that the book opened up so many doors not only for her child but for her whole family. The book is easy to read and gives families all the information they need to successfully navigate through what can be a highly complex journey. Every chapter is full of essential information about every conceivable subject around special needs and disabilities. A particular favourite with the families and staff at school is the ‘jargon buster’, which helps us all to speak and understand the same language!

In addition to *Making Sense of it All* and *Making Sense of Adult Life*, Reaching Families provides a wealth of information on their website and Facebook page, they have produced excellent fact sheets on a wide range of subjects and offer invaluable support and training opportunities on a regular basis.

During my career in special education I have seen many changes, none more important than the current reforms that place children with special needs and disabilities at the centre of planning. This creates many opportunities for more personalised and creative outcomes, which will ensure that our children and young people can look forward to a bright future with meaningful, purposeful and fulfilling lives. However, such significant change can also bring about confusion, stress and anxiety and no one is better placed to support parent through this than Reaching Families and therefore I highly recommend their resources to you!

*Lesley Dyer, head teacher*  
QEII School, Horsham
A new diagnosis can be incredibly isolating. There are so many things we want to ask. We need to speak to people who have first-hand experience of the things we are facing and truly understand what we are going through, but it is hard to know where to begin.

*Making Sense of it All* has been written for you in order to share the knowledge and experience that we have gained since our children were diagnosed. We hope that our book makes a difference to your journey, and that it offers you practical and emotional support, as well as signposting you to the local services and groups that have been a lifeline to us and our children over the years.

Since publication of our first edition in 2012 there have been sweeping changes in the delivery (and co-ordination) of education, health and social care to children and young people with special educational needs and disabilities. In addition, the benefits system is undergoing a major overhaul.

It can feel overwhelming trying to get to grips with the vast amount of change going on, make sense of the array of information available and get used to the jargon and terminology used by professionals.

We hope, therefore, that our book will be a step-by-step guide through this unfamiliar landscape so that you can make the right choices for you and your family and achieve good outcomes for your child. To this end, our third edition of *Making Sense Of It All* has been completely revised to ensure that all chapter content and directory entries are up to date. We have also added an index to ensure that you have the information you need at your fingertips.

To date, Reaching Families has distributed more than 7,000 copies of our books to parent carers across West Sussex. Thanks to external funding we are now able to give these books to parents free of charge. Many professionals also use our book and, at a recent event for clinical
commissioners, a GP told the audience that when she handed a copy of *Making Sense of it All* to a parent, she cried and said she had never been given anything so useful. This means so much to us at Reaching Families and we are incredibly proud to know that our publications are held in such high regard by parent carers and professionals alike.

We are delighted, therefore, that funding from the Big Lottery Fund has secured future editions of both books until 2019 so that we can continue our work with West Sussex parent carers to empower them and help them to make informed decisions for their children.

You may find it useful to refer to our other information resources for parent carers, which now include a series of localised fact sheets on childhood disabilities and other issues, such as meetings, DLA, sleep, sensory issues and challenging behaviour. These are available to download from our website. We also publish a companion title, *Making Sense of Adult Life*, to help parent carers and young people aged 14+ as they make the transition to adulthood – again this available free of charge to parent carers and can be ordered via our website.

Our grateful thanks go to the following organisations and professionals for their ongoing support with this book:

- West Sussex professionals who have given feedback on the chapter content: Lindsey Butterfield; Charlie Connor; the Children’s and Young People’s Continence Team; Robert Hayes; the Independent Living Team; Heather McIntosh; Michael Rhodes-Kubiak; Liam Ryan, Vanessa Sharp; Claire Williams and Linda Wilmott.

- Amaze, Brighton – *Making Sense Of It All* is based on their guide *Through the Maze*, which we believe remains the benchmark for measuring the quality of information provided to parents.

- The Reaching Communities programme of the Big Lottery Fund, which has funded the publishing of this edition.

- The project team: Sue McMillan (editor); Helen Jervis (directory updates); Charlie Rowlins (book design); as well as Lesley Dyer for the foreword and Donna and David Elston for the beautiful cover image.

*The Trustees, Reaching Families*
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 to 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 fourth edition for publication in 2019.

We hope that by using our two books, *Making Sense of it All* and *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 system as smoothly as possible.

https://westsussex.local-offer.org
'It’s like being hit with a mallet, isn’t it?’

Most of us at Reaching Families agree that one of the hardest times we have faced as parent carers is the early days, when we were first aware that our children may have a disability or additional needs.

Some of us were given a diagnosis before or just after our children were born. For others, the needs of our children have only become apparent over time, or have been acquired due to an illness or an injury.

A few of us discovered that, although it was clear that our children have additional needs, professionals were unable to give us a firm diagnosis. This can be quite common for children with complex needs, or unusual symptoms, or there may simply be no identifiable reason for the issues our children have. Not having answers or being able to put a name to our child’s condition can be exceptionally hard.

‘I expected them to be able to tell me what was wrong, and they didn’t, they couldn’t, as it were, so that was a bit of a shock. It shakes your faith a bit, doesn’t it?’

But the thing that unites all parent carers is that the immediate aftermath of realising our children have additional needs is very painful. We have to adjust the path we had planned for our family and accept that some of the things that we have dreamed of for our children may not happen. Some of us felt like we were grieving for the child we had imagined we would have and felt unsure that we could cope with what lay ahead.

We found that the most important thing was to find out how we could help our children
and one of the best ways of doing so was by speaking to parents who have been through it themselves. This is why we created *Making Sense of it All* – we hope that we can help you by sharing our experience and knowledge and that our book will support you, not only in the early days, but right through your journey through the SEND world, so that you can make informed choices for your child and family.

**Feelings around diagnosis**

Parents have very different reactions when they realise their child may have additional needs. Some may shy away from it, in the hope that things will be OK, others find that they have to convince their doctor or health visitor that their child needs further investigations.

Some of us felt completely devastated, then angry – why us? Was it something we did wrong during the pregnancy? Could we have done anything to prevent it? Why wasn’t it picked up during pregnancy? And yes, we all felt bereft: ‘this isn’t the child I expected’.

‘I was doing the reverse – I was frantically making out that it was going to be all right, although I really knew that there was something wrong... I was fighting it all along.’

It is common to feel crushingly guilty at some of the thoughts that go through our heads: ‘I won’t be able to cope, I don’t want to have to cope, this isn’t the path I had planned...’

Whatever you’re feeling at this moment – anger, despair, fear or overwhelming protectiveness – and all of us have experienced similar feelings and understand just how difficult it is to process these emotions and for a time it feels like nothing will ever be the same again.

‘To me, it was like someone had died, and it takes a long time to come to terms and to be rational about it afterwards.’

In spite of the strong feelings it evokes, having a diagnosis can be helpful. You can start to read up on the condition, join relevant local or national organisations, find out about the latest research
and, perhaps most importantly, meet other parents in the same boat. It can also be a great asset when you’re applying for various benefits to be able to say, “my child suffers from X syndrome” or “has Y disability”.

**Strategies for coping with diagnosis**

It can take anything from a few months to several years to feel like we are beginning to deal with this different life and for it to become the ‘new normal’. We all need a lot of help along the way.

It can be useful to think about what steps you can take to make sense of what you are finding out about your child. You may find these suggestions helpful:

• Ask someone to come with you to support you in the appointments. If you are given unexpected news, it can be difficult to deal with alone.
• Make a list of questions you want to ask and take it with you – don’t be afraid to raise any concerns you have.
• Take time to think about what is said and, if you don’t understand something, ask.

• Ask what will happen next, who you can speak to regularly for advice and where you can get more information.

**Getting a second opinion**

Sometimes parents want a diagnosis reconfirmed in order to feel sure they have explored every possible avenue on their child’s behalf. Some doctors are very sympathetic towards these feelings. Your child’s GP or consultant may be willing to refer you to a different consultant for a second opinion, but they don’t have to if they don’t agree it’s necessary.

Parents who can afford to might choose to approach consultants privately. Private health care is very expensive and it’s not easy to discover for yourself who is an expert in any particular condition. You may be able to get advice about this from The Patients’ Association, the Care Quality Commission or the Patient Advice and Liaison Service (PALS). You can find their contact details at the back of this book.
If your child has a specific condition, the relevant local or national support group may provide you with advice or support and some have medical experts of their own. For example, The Down’s Heart Group gives support and information to families regarding heart conditions associated with Down Syndrome. Another source of information is the NHS Choices website.

It can also help to talk to parents who have faced similar situations, or made the same tricky decision. There may be different approaches that other families have found, or simply a different point of view on the problem.

‘We were shocked when we eventually got a diagnosis, which we weren’t expecting to be serious.’

Where your child might be diagnosed

Some of us knew before our babies were born that they were likely to have some sort of disability. It’s a time for lots of questions: ‘What treatment is there?’; ‘Will my baby need surgery?’; ‘Is it life-threatening?’; ‘Where can I find out more?’ Many of these questions can be answered by your consultant, who can talk you through what is likely to happen.

Some of our babies started life on the Special Care Baby Unit (SCBU) at St Richard’s Hospital in Chichester, East Surrey Hospital in Redhill, Princess Royal Hospital in Haywards Heath, Worthing Hospital, or if they are in need of more intensive treatment, at the Trevor Mann Unit at the Royal Sussex County Hospital in Brighton.

In some cases, children are referred for further tests to London hospitals such as the Evelina Children’s Hospital, Guy’s and St Thomas’, Kings College Hospital, Great Ormond Street Hospital and St George’s.

Child Development Centres

Many children will be diagnosed or assessed at their local Child Development Centre (CDC).

There are four CDCs in West Sussex: Chichester; Crawley (with an outreach clinic at the Hilltop
Centre, Horsham Hospital); Haywards Heath; and Worthing. If you are worried your child is not developing normally and would benefit from an assessment at your local centre, you need to ask a professional, such as your GP, pre-school teacher, health visitor or consultant, for example, for a referral.

Many different specialists are based within the CDCs, including paediatricians, social workers, health visitors, clinical psychologists, dieticians, speech and language therapists, occupational therapists and physiotherapists. They work together to assess children, both individually and collectively, then plan a programme of therapy and treatment.

**Chailey Heritage**

Children with complex physical or neurological disabilities are often referred to Chailey Heritage, near Lewes. Chailey is a highly specialised centre for children with complex physical disabilities and health needs.

Two organisations work closely together on the Chailey Heritage site:

(i) Chailey Clinical Services is part of Sussex Community NHS Foundation Trust and can be accessed through a referral from an NHS clinician.

Their multi-disciplinary team offers a range of services for children and young people including medical, clinical and therapy services, rehabilitation engineering, residential short breaks and shorter community breaks.

In the Rehabilitation Engineering Unit, engineers and technicians adapt or make equipment to help with mobility and communication. Another team work on postural management. They design and adapt equipment so that children can sit, lie or stand to the best of their ability.

(ii) Chailey Heritage Foundation is a charity that includes a school for disabled children between three and 19 years, residential services from short breaks through to 52-week care, holiday
activities, post-operative care and a transitional residential service for young adults aged over 19.

Chailey Heritage School is for children and young people with complex physical disabilities, high health needs, sensory impairments and associated communication and learning difficulties. It offers education on a residential or day basis. Input from NHS nurses and therapists is fully integrated into teaching and learning within the school and into the residential services.

At the school, a variety of Augmentative and Alternative Communication (AAC) systems are used, including the Chailey Communication System (CCS), which was developed jointly by the school and Clinical Services. These systems are used to help each child reach their full communication potential.

Children who attend the school have Chailey Heritage School named as their placement in their Education Health and Care Plan (EHC Plan) or Statement, if they are yet to transfer to an EHC Plan.

**Child and Adolescent Mental Health Service (CAMHS)**

Some children with emotional wellbeing, mental health problems or behavioural difficulties may be referred to the Child and Adolescent Mental Health Service (CAMHS) for assessment and diagnosis. This includes many children with conditions such as Autism or Attention Deficit Hyperactivity Disorder (ADHD) as well as issues like anxiety and depression.

CAMHS have a team that specialises in children’s mental health including child psychiatrists, family therapists, counsellors, play and art therapists.

If you think your child needs to go to CAMHS, it’s often easiest to speak to your GP first and ask for a referral to a community mental health worker or CAMHS. You can also be referred by other professionals, such as a school nurse or teacher. It is possible to contact CAMHS directly, but they’ll want to know if you’ve tried other less specialist services first, such as the school nurse or your GP.
Early Support

Early Support focuses on giving each child the best start in life, by helping parents-to-be and families with young children. The aim is to work holistically with families as soon as possible, as the more fully families are supported in the early years, the less likely they will need higher levels of help later on.

In April 2017, many support services were brought together under the umbrella of ‘Integrated Prevention and Earliest Help’ (IPEH) within WSCC. However, for parent carers, the way in which the majority of services are accessed has not changed. You can ask for support through many channels, including your health visitor, local Children and Family Centre, Early Years Hubs, the Early Childhood Service, Family Support or West Sussex Young Carers, for example.

You can find out more about types of Early Support in ‘Help with daily life’, page 117.

Finding out more

If your child receives a specific diagnosis, you may wonder where you can get information about their condition or disability.

Reaching Families has published a series of localised fact sheets on childhood disabilities, which may prove useful when you are beginning to find out more about your child’s condition, their needs and what support is available to them locally.

Each of our fact sheets is available on our website. They combine clinical information on individual conditions with local information on relevant support that is available. In time, we hope they will be given to parents by doctors and community paediatricians when they are given their child’s diagnosis.

We have also published a second series of fact sheets on a range of other issues that may be useful when you are beginning to learn about your child’s needs and how you can support them. The
fact sheets cover a wide range of topics such as sleep issues, DLA, attending meetings and sensory issues. These too are localised and contain information on the support that is available to parents in West Sussex.

Many of the most common conditions have local groups, which are listed at the back of this book. We also list many of the national organisations that can offer support.

Another good place to start is the NHS Choices website which has a fairly comprehensive A to Z list of illnesses, conditions and disabilities. BUPA also has a similar online directory.

Contact a Family, which offers support and information to parents of children with disabilities, has a large resource library on its website: www.cafamily.org.uk. It covers a range of subjects including: support for parents; understanding genetic conditions; rare disorders; and sources of medical information.

The Council for Disabled Children also has a wide range of resources to support parent carers. You can find out more at: https://councilfordisabledchildren.org.uk.

If your child has a rare condition it may be more difficult to get the information you need. However, Contact a Family produces a comprehensive directory of specific conditions and syndromes with details of their family support networks. They also coordinate a network for parents whose children have a rare condition or no specific diagnosis.

You can also get information and advice from Unique, the rare chromosome disorder support group, or Syndromes without a Name (SWAN). You can find contact details for these organisations at the back of this book.
Someone to talk to

‘Being listened to – that’s really important – to have people around who are prepared to listen to you, because it is important to say how you’re feeling.’

Finding out your child has special needs can be very painful. Sometimes, years after we first heard the news, many of us still relive everything that happened at that time.

Our children are all very different, but the one thing we all have in common is the need to talk about what happened. For some of us, having a supportive family can be enough.

Some of us met someone who was a marvellous shoulder to cry on. Others were pointed in the direction of a parent support group or counsellor.

Groups for specific conditions

‘That’s what I found the most helpful – that other parents had gone through the same things as me, and you know they’re still around – sometimes you tend to think you are the only person that this has ever happened to.’

Especially in the early days, many parents find that joining a parent support group specifically for our children’s condition is a lifesaver. If your child has just been diagnosed and you’re frightened of what might lie ahead, meeting a parent with an older child with similar needs to yours can make you feel more able to manage. People whose children have similar needs can be a great source of support and information, and they may also become good friends.

The following is a list of the major support groups for parents
operating across West Sussex. Contact details can be found in the local directory at the back of the book; most also run Facebook groups:

- **ADHD Support Group** holds regular meetings in Worthing and also has a Facebook group.
- **Autism by the Sea** is a support group for parents of children with autism in Worthing and the surrounding areas.
- **Autism Support Crawley** Support group for parents and carers of children and adults on the autism spectrum or with social communication difficulties. Holds regular meetings in Crawley, dates and venues can be found on their website.
- **Autism Sussex** holds workshops, and gives advice and support to families across Sussex, as well as holding groups and providing 1:1 outreach support to children and young people.
- **Chichester Down Syndrome Support Group** runs regular social evenings and family outings for families of children with Down Syndrome.
- **Dame Vera Lynn Children’s Charity (DVLCC)** supports children under 5 with cerebral palsy and motor learning difficulties, and offers a parent support network as part of its services.
- **Horsham Parent Send Support** is a support group for parents of children with social communication needs or autism. For more, join their closed Facebook group.
- **Hyperactive Children’s Support Group** provides information and support to families of children who have ADHD or are hyperactive.
- **Parenting Autism Together in Horsham (PATH)** is a support group for parents of children with autism, based in Horsham.
- **Parents for Autism** is a Worthing-based support group for parents, relatives and carers of children and young people with autism.
- **Puzzle Pieces** is a parent-led support group for parents with children on the autistic spectrum, based in Bognor.
• **Reaching Families** runs support groups called Umbrellas for parents of children in mainstream schools at venues across the county.

• **Special Families** is a support group for families with a wide range of disabilities and special needs in East Grinstead and the surrounding villages.

• **Sussex Autism Support** offers information and support to parents of children with autism.

• **Worthing Kids and Dapper Snapper (WKDS)** runs a support group for parents of children with Down Syndrome and other disabilities from the Worthing area.

• **Worthing Scope** runs a support group for families and carers of children with cerebral palsy that meets on the last Saturday in the month.

Parent-led general support

‘What I found most important was finding the right person on your wavelength, who you actually can get on with as a person and has got the added thing of having an appropriate special needs child. I was lucky – I had this girl down the road, but she’s moved now, and I really miss her.’

There are a number of general support groups and projects in West Sussex for parents of children with special needs, such as Parent and Carers Support Organisation (PACSO) and Carers’ Support West Sussex.

Elsewhere in the county, Kangaroos in Haywards Heath holds family days out, which provide the opportunity to meet other parents. St Matthew’s Church in Worthing runs a parent and toddler group called SNAPS.

West Sussex now has 44 children and family centres, eight of which are Early Years hubs, offering additional support for children with SEND. We know that many parents use their facilities to support their child and to meet
other parents. You can find details of your local centre at the back of this book or at: www.westsussex.gov.uk/cfc.

Nationally, Contact a Family (CAF) operates an online forum, which you can access via their website: www.cafamily.org.uk. The forum enables families affected by disability to get support by speaking to others about the issues that affect them. The parenting websites Mumsnet: www.mumsnet.com and Netmums: www.netmums.com, both have forums with devoted SEND areas where you can chat to other parents.

Community support groups

There may be parent groups in your area that are not specifically for parents of children with special needs. If you are a single parent, Gingerbread and Single Parents Information Network (SPIN) may be able to put you in touch with others in similar circumstances. Working Families is another useful group, which has a campaign called ‘Waving Not Drowning’ for parents trying to combine paid work with caring for children with disabilities.

Support from professionals

There are many local and national organisations that can offer information and support to parent carers. Some cater for certain disability groups; others are for anyone who may be caring for a child with special needs.

Home-Start

This charity is designed to support families with at least one child under five. The programme provides trained volunteers, who are usually parents themselves,
to provide emotional support, practical help and friendship to other parents of young children.

There are three Home-Starts in West Sussex: Arun, Worthing and Adur; Chichester and District; and Crawley, Horsham and Mid Sussex (Home-Start CHAMS). Their contact details are listed at the back of this book.

**General support**

Reaching Families, Wellspring, and the West Sussex Parent Carer Forum (WSPCF) are the main sources of information and advice for parents in West Sussex.

The West Sussex Local Offer lists a wide variety of services available to children and families as well as providing information on SEND. See page 8 for more details.

Nationally, Contact a Family offers information, advice and help for parents of disabled children and also have a helpline, the number for which is at the back of this book. Go to: www.cafamily.org.uk.

**Training for parent carers**

Reaching Families provides training on a number of subjects for parents at various locations and venues across West Sussex. Subjects covered include: behaviour; benefits; communications; education; sleep strategies; and stress and resilience. We deliver our training in a roadshow format, which means we deliver each workshop at multiple locations. To find out when we are next delivering training in your area, please take a look at our website. We would also recommend joining our Facebook group and mailing list by sending an email to: info@reachingfamilies.org.uk.

A number of other organisations provide training to parent carers in West Sussex. If your child is on the Autistic spectrum we would recommend contacting Autism Sussex.

West Sussex Parent Carer Forum delivers training on an array of subjects. They also hold regular ‘coffee, cake and networking’ events for parent carers, where...
they can meet services and organisations from around the county. For further information contact WSPCF. Tel: 01903 726188 or email: office@wspcf.co.uk.

**Counselling**

*The ability to speak to someone you know will listen and know what you’re talking about – that’s the most important thing for us – to be listened to and to be taken seriously. I know if we didn’t have that we wouldn’t survive... it literally keeps our family together.*

If you think you’d benefit from a place where you can talk openly with one person about how having a child with SEND is affecting you, think about counselling. There are various kinds of services available in this area. Help may be short- or long-term, it may be free or involve payment.

Carer’s Support West Sussex provides an Emotional Support Service, with counselling sessions and other support for emotional wellbeing and relaxation, as well as a telephone support service.

Carer’s Support and the West Sussex Parent Carer Forum work in partnership to provide the Carer’s Wellbeing Fund (also known as a Parent Carer Grant). Parent carers can apply for a grant of up to £300 which can be used flexibly to enhance their health and wellbeing. Call: 0300 028 8888 (Carer’s Support) or 01903 726188 (West Sussex Parent Carer Forum) to ask for an application form.

There are also a number of generic counselling services in West Sussex, some of which provide counselling based on a client’s ability to pay. Offington Counselling Service in Worthing works in such a way, as do the Arun Counselling Centre and Chichester Counselling Service.

**Relationship counselling**

Some of us have found that as a couple our challenges have brought us closer together.

However, having a child with SEND can put an additional strain on relationships. It’s harder to have any quality time
and after a challenging day, it’s all too tempting to retreat as emotionally you feel you have nothing left to give.

‘We’ve found weekends away absolutely essential. We save up, we go to a hotel. Our carer has Jane, and somebody else has to have the others.’

If you’re beginning to see warning signs this is happening to you there are groups that can help, for example, Relate, which has three branches in West Sussex.

**Family Support**

This is a West Sussex service providing personalised support, including home visiting, for families with children and young people aged up to 19 (25 for young people with SEND). Support workers will help parents by discussing strategies and solutions to everyday family issues and introduce you to local family activities.

To find out more, speak to your local Children and Family Centre (see Local directory for details) or your health visitor, GP, midwife or pre-school.

Child Development Centres also have specialist health visitors/nursery nurses, who work as part of the multi-disciplinary team supporting families.

**Children and Family Centres**

Many of the services you might need can be accessed through your local Children and Family Centre. These centres support families with children under the age of 11 with a focus on under fives, or up to 19 years if your child has a disability and needs childcare. They offer access to:

- Integrated care and education for under fives.
- Family support and outreach to parents.
- Child and family health services.
- Links with Jobcentre Plus.
- Help to find childcare for children up to 19 years old.

There are 44 Children and Family Centres in West Sussex. You can find their contact details at the back of this book, or on the West Sussex County Council website.
Early Years Hubs

There are also eight Early Years Hubs, which are located in Children and Family Centres (CFC) around the county. The hubs offer additional services, advice and activities specifically for children with SEND.

Each hub runs ‘Play and Learn Plus’ sessions and some offer the chance for your child to access sensory areas and sensory toys. Sessions are also an opportunity for you to meet other parent carers. All hubs are wheelchair accessible and some also have hearing loops.

The hubs are based at: Bognor Nursery School and CFC; Boundstone Nursery School and CFC (Lancing); Chichester Nursery School and CFC; Durrington CFC; East Preston CFC; Horsham Nursery School and CFC; Langley Green CFC (Crawley); and Sidney West CFC (Burgess Hill). For contact information, see the Essential contacts page 155.

Toy libraries, sensory toys and equipment

Toy libraries are based in West Sussex Children and Family Centres and some local libraries and resources can be borrowed by all families. In addition, specialist sensory stock is held at the following Children and Family Centres: Billingshurst; Bolney (Mid Sussex); Boundstone (Lancing); Chichester; Durrington (Worthing); Felpham; Horsham; Langley Green and Ifield (Crawley); and Petworth.

To find out more, ask at your local Children and Family Centre or search the Family Information Service website.

Your local Portage office may also be able to advise you about toys to help your child’s progress. Again, their details can be found at the back of this book.

Bereavement

Some parents live for years knowing that their child has a life-limiting condition. Some of you may have already lived through that.
When a child is terminally ill it is a desperately painful time for families. Many people don’t know what to say and, scared of saying the wrong thing, end up saying nothing at all.

Those of us who have lost a child, however, often want to talk about them – we long for people to mention their name and share memories. Frequently, we have been very closely involved with our child’s physical and medical care and suddenly this has all stopped. There’s a huge gap. Some of us find it invaluable to talk with other parents who have had the same experience, or someone who will listen and understand.

Hospices

Children who are terminally ill and need nursing care may spend time in a hospice, an environment in which most children can feel safe and receive specialist care.

Hospices also offer respite for children who have complex physical and medical needs, and support for their families. They are bright, sunny places. Parents often find the support they offer is invaluable.

The main hospice used by families in West Sussex is Chestnut Tree Children’s Hospice, near Arundel. This is an excellent facility with highly trained staff who are extremely experienced in caring for children who are terminally ill or have complex needs. They are also very skilled in caring for carers and amongst other things offer bereavement support after a child has died.

Professional support for bereavement

For parents in this situation, there are a number of sources of support that may prove useful. Child Bereavement UK runs a confidential helpline that gives support and guidance to bereaved families, as well as having a website with many resources for parents and the wider family.

The Child Death Helpline is run by volunteers who are themselves bereaved parents. They are supervised and supported by teams within Great Ormond
Street and Alder Hey Children’s Hospital. The helpline is open every day of the year and supports parents and family members who have lost children of any age, even those in adulthood.

Another option is Compassionate Friends, who provide information, a helpline, befriending and support to parents, grandparents and siblings who have suffered the death of a child.

Cruse Bereavement Care has three branches in West Sussex: Chichester and Arun; Crawley, Horsham and Mid Sussex; and Worthing and District. They have more than 90 trained bereavement volunteers, some of whom are specially trained to work with bereaved children and young people aged between five and 18 years.

Each branch also has a telephone answering service and friendship groups that meet regularly. Mid Sussex branch also offers a telephone counselling and Worthing and District also offers a fortnightly drop-in service.

Winston’s Wish, who specialise in working with grieving children, runs a helpline, an email service and also has a variety of resources on their website.

**Practicalities**

As if coping with grief isn’t enough, there are funeral arrangements to sort out, too. Funeral directors do not charge for babies’ and children’s funerals and some will provide extra support for families who have lost a child.

You may also want to create a ‘memory box’ containing maybe a lock of hair, first teeth, photographs, a handprint or your child’s special toy. It may also help to get your child’s friends and siblings together to celebrate their life.

‘I recently went to a thanksgiving service for a young disabled child. It was lovely – showing what he liked to do, painting, music, and so on. At the end, his five classmates, all in their wheelchairs, each let off a balloon outside to say goodbye. It was very special.’
As you’ve no doubt gathered by now, the road ahead may be bumpy at times. Getting the best for your child can take a lot of effort, but it can be done. Here’s a selection of our top survival tips for maintaining your sanity and getting the best outcomes for your child.

**Talking to professionals**

“All parents worry about whether they are doing the best by their children, especially when you know that if you don’t get the best for your child they’re not going to get anywhere on their own.”

**Write it down**

- Keep a notebook or diary, you wouldn’t believe how much information you start to collect.
- Note the date of any telephone calls you make and any letters you receive, and keep copies of anything you send.
- Take notes of conversations as you may need to refer back to them at a later date.
- Start a file in which you keep copies of all the letters and reports you get about your child.

**On the phone**

“Always be extra-friendly with receptionists and secretaries, they are your gateway to the chief!”

- Make sure you’re talking to the right person, or persist until you get hold of them. Don’t be put off by someone being hard to reach. Note down when they’ll be back and call them then.
- Try to be patient – no one else is as emotionally involved as you are, but be prepared to be firm if necessary.
- Always be friendly to receptionists and secretaries and let them know how much you appreciate their help.
• Get to know who’s who in the place you’re calling and go to the top if you need to.
• Be specific – plan out what you want to say before you ring.

At appointments

‘When you’re presenting your case, like at social services, sometimes you can just get so upset, because you’re going through all the worst things, aren’t you? Trying to explain to somebody what it’s like can be really upsetting…’

• Take someone with you for support, and ask them to take notes.
• Ask the professional if you can have copies of any notes they take.
• Don’t be afraid to ask questions, especially if you don’t understand what’s been said. If you’re still confused, ask again.
• If English is not your first language, ask for an interpreter.
• Be prepared for clinics running late and take activities to occupy your child, or ask if your child can be seen before others who are more able to wait.
• Choose who is present and say no if onlookers might make you or your child feel uncomfortable.
• Have faith in your own experience of your child, you know your child better than anyone else.

And afterwards

‘I complained to the consultant about the way I was treated in hospital. I wrote this great long letter, and I was so impressed with myself afterwards, because all the grievances came out, and I thought, ‘Oh God, she’s never going to speak to me again.’ But I sent it off, and she was excellent, and it never happened again…’

• Follow up appointments with questions in writing if you think of them later on.
• Ask when you can expect replies to requests – make a note in your diary and follow it up if you haven’t heard by then.
• Make sure you meet deadlines – it’s in your interests to think ahead.
• Make sure professionals know if you’re unclear or unhappy about anything, a brief word or telephone call may be all that is needed to sort things out.
Survival strategies

• Let people know in writing if things start to go badly wrong – don’t wait until you’re in crisis.
• Don’t feel bad about changing specialists if you don’t get on or feel their approach is wrong for you or your child.

‘I changed my physio – I knew she’d be better off with this other girl. She used to sing a lot and Alex loved the singing. It was a real trauma to change, but I was so pleased that I’d done it, because she was so much better.’

Looking after your child

‘I just found that you do everything, everything that came: “Yes, she’ll do that, oh yes, we’ll go to that, yes, we’ll do that.” I tried to carry on doing everything and then I couldn’t manage, really. But then it needed someone else to come in and say, “It’s all right, actually, you don’t have to do all these things, and Alex will be perfectly fine if she doesn’t do these things.” I felt she needed so much input.’

• Remember, not every minute of your child’s time has to be filled with therapy – do things you both enjoy without feeling guilty.
• Find out about your child’s condition – national organisations can give support, advice, and perhaps information on the latest research into your child’s condition.
• Ask your support group to help. Remember, they’ve heard it, seen it, and been there before. They may be able to go to meetings or reviews with you, or write letters of support for you.
• Explore financial help, don’t feel embarrassed about asking for it – not all benefits are means tested.
• Ask other parents about their experiences, they will often be your best source of information.
• Teach your child to be as independent as possible, it will make your life easier in the long run.

‘Rose is good now, she takes her own medicine, and she has done for two years, because she was on such frequent doses. Looking ahead, the only way to get through it was to teach her to do what she could as a normal thing, every day.’
Looking after the whole family

• Try to do things as a family – it’s easy to concentrate too much on your child with SEND and hard to strike a balance.
• In the early days, or during a crisis, appoint someone outside the immediate family to be the contact person for news. Ask them to pass on messages and let people know when they can visit.
• Don’t be afraid to take the phone off the hook and enjoy what peace and quiet you can.

‘It’s looking ahead at a strategy that is not going to crack any one of you up – you can’t have a weekly routine that’s going to leave you exhausted.’

Looking after yourself

‘People think you’re coping, and you’re not. People think because you’re not falling apart all the time and going round in shrouds of grey, they think everything’s fine and hunky-dory.’

• Don’t be ashamed to say, “I can’t do this any more.” Ask for help when you need it.

• Find someone who will listen and take you seriously, someone you get on with and trust.
• Be selfish – if you go under everyone will suffer. Put yourself first for once.
• Find ways of pampering yourself – have a massage or some reflexology. It needn’t be expensive – some organisations provide special cheap, or sometimes free, treatments for carers.
• Be prepared to deal with well-meaning but insensitive comments sometimes, even from family and close friends. In time, you’ll find you get better at hearing what people mean to say.
• Make sure any groups you join are supportive. If you come home feeling worse, it’s not worth it.
• Have an outside interest, like work, a sport, or hobby. Having somewhere to go where you’re treated the same as anyone else puts things back into perspective.

‘I play sport – that’s my stress relief. I think it’s essential, and nobody asks you how your child is – I’m a person! It keeps your mind and body together.’
'My family is different to other families, but that’s okay. It’s different, but special.'

When your child is diagnosed with a disability, many families feel as if life has been turned upside down. The immediate focus tends to be on finding out more about the disability and making sure you put in place the right support to meet your child’s needs. However, it is also very important to make sure that other children in the family understand what the diagnosis means and are given lots of support as they adjust to the changes.

There are many positive things about being a sibling of a child with SEND. Siblings often learn new skills, such as sign language or first aid, and feel really proud of their knowledge and achievement. Yet it can also be a mixed experience. Throughout their lives, brothers and sisters share many of the concerns and worries that their parents experience, such as feeling isolated, needing information, concern for the future and the demands of caring.

As well as having lots of positive feelings about their sibling, brothers and sisters of children with SEND can experience a wide range of complex emotions:

- Siblings can feel lonely at times. It could be that they find it difficult to talk to anyone about their brother’s or sister’s needs or feel they can’t invite friends home. Siblings may spend more time on their own while parents care for their brother or sister.

- It is a completely normal part of a sibling relationship to feel angry sometimes. Children can get angry if they have been hurt, or had their possessions
broken by their sibling, or if they can’t do something or go somewhere because of their sibling’s needs.

- Embarrassment can be uncomfortable to experience and can go hand in hand with feelings of guilt. People can stare at people who are different, and some may even make comments. Siblings can experience feelings of hurt and embarrassment in this situation and then feel guilty for having those feelings.

- Feelings of worry can include: concern for their brother or sister, especially if they have health needs; worrying about their parents; worrying about all the things that parents are stressed about; and worries about what the future holds.

- It is normal for siblings to feel sad at times. Sadness can occur because of particular events, such as their sibling being unwell and having to stay in hospital, or it could be because their brother or sister isn’t like other brothers and sisters.

Siblings may feel sad that they can’t always do the same things that other children and families do.

- Jealousy and resentment can be common emotions experienced by many siblings, regardless of disability. Sometimes, sibling children can have feelings of jealousy about the amount of time and attention that is spent on the child who has SEND. Resenting their brother or sister because of this is understandable but at the same time it is something siblings should be encouraged to talk about.

‘I feel bad whenever I achieve something that my sister can’t.’

Parents’ time and attention

Often, siblings don’t get enough individual time with their parents. Parents of children with SEND have a lot to juggle and as a result, siblings can receive less time and attention. Children can understand that their brother or sister needs more help, but it can still feel unfair.
‘Sometimes I feel jealous of him because my parents make a lot of fuss over the things he does, but not as much when I do good things.’

Caring responsibilities

Many siblings help their parents to look after their brothers and sisters in a variety of ways. It may be that they supervise while parents pop into another room, help with feeding or drinking, or carry out household chores. It is a part of family life that members help and support each other. However, it is important that siblings are not carrying out too many care tasks and that they have time to do their schoolwork and spend time with their friends.

Bullying

Sadly, bullying can be very common. Sibling children can get teased or bullied because they have a brother or sister who is different, or because they can’t always do things that other children can. Siblings are often very protective of their brother or sister and perhaps feel angry and sad when they are teased. However, sometimes siblings may experience conflicted loyalties between family and friends and may take part in teasing the disabled child. Extreme feelings of guilt usually follow. Because of these experiences, siblings of disabled children can be more sensitive to others’ feelings.

Being hurt

‘I have shouting matches with my sister. We don’t always get on, but I love her – just like other siblings I suppose.’

Some children have brothers and sisters who may hurt them due to their SEND. They may get bitten, hit, have their hair pulled, or they may be verbally attacked. This is, of course, upsetting but can also be confusing and difficult for the sibling to understand. Regardless of the reason for the challenging behaviour, when a sibling is hurt by their brother or sister it can be frightening, hurtful and distressing. Sibling children need their parents to try to explain what has happened and why, and also to take steps to avoid further incidents as much as possible.
Missing out

It can be difficult for sibling children to have friends round to the home for practical reasons. Also, siblings may not want to invite people as they may feel uncomfortable or embarrassed about their brother’s or sister’s SEND. Providing care for a disabled brother or sister may impact on a child’s ability to complete schoolwork, attend clubs or have one-to-one time with parents. There may be limited opportunities to go on family holidays and days out because of challenging behaviours, accessibility issues or financial restrictions.

Out of the loop

‘Looking back, the single most important thing to me was to be told the truth and be kept informed.’

Often, siblings do not receive accurate and age-appropriate information about their brother or sister’s condition. Without this knowledge, some siblings may try to fill in the gaps themselves and make all sorts of wrongful assumptions. This can create feelings of self-blame and guilt. Providing siblings with the correct information and answering any questions they may have should prevent some of these feelings and ensure that they feel informed and involved.

The future

What is going to happen in the future is a huge concern for parents, but it is also something that can be a worry for siblings, too. The thought that they may be responsible for the care of their brother or sister in the future can be overwhelming, so it is extremely important that this is discussed as a family.

Ways to help

• Recognise and acknowledge their worries. Always take time to listen to any questions or concerns.
• Find activities that siblings can do with their brother or sister.
• Communicate. Keep them informed and up-to-date. Ensure they have the correct information and haven’t made assumptions.
• Make sure that siblings get one-to-one time with you.
• Provide opportunities for siblings to meet their friends.
• Limit the type and amount of care that the sibling does.
• Have a safe place for your sibling child’s treasured possessions if damage is likely.
• It is important to help sibling children to recognise and acknowledge their role in the family. Improving communication and sharing feelings will help with this.
• Be consistent and as fair as possible.
• Role-play can help as a way of rehearsing how to respond to teasing or bullying.

Young carers

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, email youngcarers@westsussex.gov.uk, or go to: www.westsussex.gov.uk/youngcarers.

Grandparents and the wider family

Sometimes, relationships within a family can be difficult. When a child is born with or gets a diagnosis of SEND, this can add to stresses and strains in relationships.

Grandparents, along with other close family members may go through the same cycle of
emotions as parents: anger; grief; denial. Some individuals can find it extremely difficult to come to terms with. It is important, however, to recognise the contribution that grandparents and wider family members can make in supporting families with disabled children.

Parents who have disabled children often face additional caring responsibilities and emotional demands and this can result in feelings of stress. Support from close family is vital for parents in terms of adjusting to change and coping with stress.

Grandparents can play an important role by providing the family with practical and emotional support. Often, grandparents feel that having a child with SEND in the family has given them greater understanding and compassion, and it can help to bring the family closer together. However, for some family members it can bring feelings of being under pressure to offer help and support.

Grandparents and the wider family may not always agree with the way that parents are raising their children. This can be a source of conflict, especially as it is vital that children with SEND have a consistent approach as difficulties can be avoided by everyone responding to the child in the same way.

Grandparents can play a key role in caring for children with disabilities so that parents can have a break or some one-to-one time with their other children. They can also support siblings by taking them out and offering them a break away from home.

**Top tips for grandparents and close family:**

- Offer whatever support you can realistically manage – don’t wait to be asked.
- Follow the parents’ lead.
- Listen and give advice if requested.
- Focus on the child, not the diagnosis.
- Helping with phone calls or accompanying parents to meetings can relieve pressure.
• Be there, even if it’s just at the end of the phone.
• Help with practical tasks such as cooking a meal or doing the shopping can make a big difference.

Parent carers can support grandparents and other family members by keeping them up-to-date with what is happening in the family and helping them to learn about the child’s SEND via support groups, websites and Facebook pages.

Asking for help from family can be difficult but doing this and being clear about the support you need can be a way forward. Sometimes, family members may wait to be asked as they may feel that they would be interfering if they offer help first.

Giving grandparents time and opportunities to get to know the child is so important. Having a close relationship can strengthen the whole family.

If grandparents or wider family are playing an active role in caring for a child with additional needs, parents might consider inviting them to take part in reviews, meetings, appointments or events at school.

**Local organisations**

• **Ashdown Club** (Worthing) offers support to families of children and young people with special needs. Sibling sessions are available in some school holidays. Tel: 01903 528607, email: ashdown@guildcare.org, or go to: www.guildcare.org/ashdown-centre.

• **Autism Sussex** runs regular support groups for siblings of children with autism. For more information, please telephone: 0345 450 0060, or email: enquiries@autismsussex.org.uk. www.autismsussex.org.uk.

• **Broadbridge Heath Leisure Centre** (Horsham) runs Discovery Fun Days for disabled children, their family and friends. The activities include: a bouncy castle; trampolining; sports; arts and crafts; as well as use of their purpose-built sensory room. Tel: 01403 211311. Email: enquiries@broadbridgeheathleisurecentre.co.uk
• **Chestnut Tree House** runs support groups for the siblings of children who are cared for by the organisation and those who have been bereaved. Tel: 01903 871800. www.chestnut-tree-house.org.uk.

• **Gully’s Day Out** provides opportunities for disabled children and young people to access some of Sussex’s top attractions and leisure facilities. Tickets are limited and must be requested through the team. Tel: 01273 668590, email: gullysdayout@albioninthecommunity.org.uk.

• **Horsham District Sport Development’s** Reaching Higher Activities (5 to 18 years) offer term-time weekly sports and arts groups, as well as multi-sports and sensory days during the holidays. Siblings and friends are welcome. Tel: Kim Roberts on 01403 215631, email: kimberly.roberts@horsham.gov.uk www.hdsd.org.uk.

• **Lodge Hill Trust** holds Family Fun Days, where needs, likes and dislikes are taken into consideration. Relaxed, friendly atmosphere, where everyone can enjoy outdoor and indoor activities as a family and with friends. Tel: 01798 831411, or go to: www.lodgehill.org.uk.

• **PACSO** provides holiday clubs and family days for disabled children and their siblings in Chichester and Arun. Tel: 01243 533353, email: admin@pacso.org.uk. www.pacso.org.uk.

• **Short Breaks for Disabled Children** runs holiday clubs, after-school clubs, buddy schemes and short breaks at home or in the community, some of which are open to siblings. Please tel: 0330 222 2562, or email: short.break.team@westsussex.gov.uk.

• **Time Aside’s** sensory art workshops provide creative fun for the whole family, using a rich array of materials. The sessions meet communication, access and esteem needs in a relaxed, fun atmosphere. The sessions are for all ages and levels of need, with sensory area and refreshments available. No need to book, drop-ins will be warmly welcomed. Dress for mess.
Tel: Sueloo on 07792 903236.  
Email: sueloo@timeaside.com  
or go to: www.timeaside.com

• **West Sussex Young Carers**  
provides direct support for young people with caring responsibilities. Please tel: 01903 270300, or go to: www.westsussex.gov.uk/youngcarers.

**National organisations**

• **Barnardo’s** runs projects to support young carers and siblings of children with learning disabilities. Go to: www.barnardos.org.uk/what_we_do/our_projects/young_carers.htm.

• **Contact a Family** for more information, tel: 0808 808 3555, or go to www.cafamily.org.uk.

• **Grandparents Plus** for information, tel: 020 8981 8001 or www.grandparentsplus.org.uk/disability.

• **Sibs** is a website for brothers and sisters of disabled children and adults. Go to: www.sibs.org.uk, or: www.youngsibs.org.uk.
When children have SEND, it can be tricky to anticipate how much extra help they will need and how much it will cost, but for many families there will be additional expenses, which soon add up.

Some of the things that you may have to find money for include: travel expenses to and from hospital, parking costs if you drive, additional loads of laundry, and special diets. Some parents also find they are unable to return to work, due to the high level of care that their child needs.

All these things can be a strain on the pocket, but many families are entitled to extra benefits or other financial help, which can make all the difference.

This chapter focuses on the main disability benefits and sources of financial help for parents who have a child with SEND. It also includes information on grants, which are available from both the government and charitable sources, and other additional benefits available to families on low incomes.

**What is Disability Living Allowance (DLA)?**

Disability Living Allowance (DLA) is a benefit for children under 16. It is often the first benefit that parents claim and it’s also a ‘passport’ to other sorts of financial help. This means that if your child gets DLA you may be entitled to other benefits, too.

DLA is paid every four weeks. It isn’t taxed, or means-tested, so your other income isn’t taken into account when an assessor is deciding whether you meet the criteria to be awarded DLA. You can claim DLA if your child needs more help or looking after than other children their age because of their SEND.
If you are considering claiming DLA it can be useful to note down all the ways in which you have helped your child day and night over the past few weeks. This will help you to answer the questions on the application form.

When you think about it in this way, you may be surprised how much extra help you give your child. Many of us underestimate just how much time and effort we put in, as after a while it becomes our everyday life. We forget about all the careful planning and adjustments we make, even for something as simple as popping to the shops for a few essentials.

‘When I was filling in my DLA form, I realised that there’s so much I do without a second thought, because this has been my ‘normal’ since Sophie was born.’

What counts as help?

Lots of things count as help. Examples include things such as the need to teach your child skills that other children pick up naturally, to always being ‘on duty’ because your child needs close supervision, or the difficulties that something as straightforward as a trip to the supermarket may bring.

Many of our children need help to be understood, make sense of what’s going on around them, or to manage difficult feelings. Some children need ‘hands on’ help with everyday activities like dressing, washing, toileting, learning to play, or get on with other children. Your child may need you to monitor a medical condition, give medication, help using special equipment, or to carry out a therapy programme. Or perhaps your child needs your help to get out and about, or needs you to keep an eye on them to stay safe.

Some children need much more help than others of the same age. But even if your child needs extra help with just some things, it is worth applying for DLA.

How can I get the forms?

You can apply online, or download the DLA application form at: www.gov.uk/disability-living-allowance-children.
Do be aware, however, that the form is 70 pages long, so it can be costly and time-consuming to print, so you may wish to ask for a paper copy to be sent to you. You can do so by calling: 0345 712 3456, or textphone: 0345 722 4433 (Mon-Fri, 8 a.m. to 6 p.m.).

Another advantage of requesting the form by phone is that it will be date stamped and, as long as you return it before the deadline, DLA will start from the date on the form if an award is made.

When you call, be clear you are claiming for a child and not yourself. Tell them your child’s age, so that you are sent the right claim pack. The application form you need, DLA1A, is different to the one for adults. If your child is nearly 16, you will be asked to fill in an application for Personal Independence Payment (PIP) instead.

You can find out more about PIP in our companion title, *Making Sense of Adult Life*. To order a free copy, or download a free PDF of the book, go to: www.reachingfamilies.org.uk.

If your claim is successful, DLA is payable in two parts – care and mobility components. You can claim either or both and there are rules about what you can claim.

**The care component**

You can claim this if your child needs help with ‘personal care’, that is, looking after themselves and this includes things like keeping safe and communication. You can claim this part of the benefit at any time, as long as your child has needed the extra help for at least three months and will continue to need that help for at least another six months. There are three rates at which it is paid:

- **Lower rate:** if your child needs some help during the day or the night.
- **Middle rate:** if your child needs more help during the day or at night.
- **High rate:** if your child needs help day and night.

**The mobility component**

You can claim this part of the benefit if your child needs extra
help getting around. There are two rates for this:
• Lower rate: if your child needs someone to keep them safe or help them to find their way around. It is payable to children from the age of five. Many primary age children are still learning how to get about and stay safe on streets and in parks near home. Therefore you will need to show how much more help your child needs than others of the same age.
• Higher rate: if your child’s ability to get around is severely restricted by their disability. This is payable to children from the age of three who are unable to walk independently. If your child is almost three and already receives the care component of DLA at the higher rate, you should be contacted and asked if you wish to make a claim for the mobility component.

More about the higher rate mobility component

You may not have to pay road tax on the vehicle used by your disabled child if they are awarded the higher rate of the mobility component. You can get a Vehicle Excise Duty (VED) exemption form from the Disability Benefits Unit dealing with your child’s claim. Ask for a INS216 so you can apply for a certificate of exemption from the DVLA, to prove that you do not have to pay vehicle tax.

Technically, the car is only exempt while it is being used solely by or for the purposes of your disabled child. However, your child does not have to be in the car every time it is used. As long as they use the vehicle ‘substantially’ this is perfectly acceptable.

Your child will be entitled to a Blue Badge

This allows the holder to disregard some parking restrictions, making it much easier to park much closer to places you are taking your disabled child to.

West Sussex County Council is not obliged to provide Blue Badges to disabled people who do not receive the higher rate of the mobility component of
DLA. However, if this is the case for your child it may be worth asking your child’s consultant if they will support your application by writing a letter. It really helps if they can. When you apply, the parking officer will write to your child’s GP. So, to be sure they have a good grasp of your child’s needs, ask that your GP is copied into the letter from the consultant.

The Blue Badge is also available to families with children under two who, because of their medical condition, need to travel with bulky medical equipment or be close to a vehicle for emergency medical treatment.

**Sticking to the Blue Badge rules**

If you display the badge back to front, or with the expiry date hidden you are likely to get a parking ticket. Most importantly, if your child is not in the car, it is an offence to display the badge, unless you are on your way to pick up your child, or you have just dropped them off.

You can get a Blue Badge application form by calling: 01243 777653, or by downloading a copy at: www.westsussex.gov.uk. You can also use the mobility component of your child’s DLA to lease or buy a car or a wheelchair, under the Motability Scheme. See page 56 for further details.

**Making a DLA claim**

For both the care and mobility parts of DLA, you have to show that your child’s needs for care or supervision are ‘substantially in excess’ of the needs of other children the same age, who do not have an illness or disability. It’s a good idea to send supporting information from professionals working with your child, because whatever you say needs to be backed up.

The forms are long and detailed and it’s worth getting help to fill them in. Other parents who have claimed DLA and have children with similar needs can be a great source of information about what to say and what not to say.

‘It’s daunting and you need someone who knows what they are doing to help you.’
**Tips**

- Allow at least five to six hours to fill in the pack and give it a high priority. Awards are made for two to three years at a time and can really help your family to manage the additional expenses, so it’s worth spending time on the form to get it right.
- There are two ways to fill the form in. You can either download an electronic copy, which you can fill in on your computer. This is quite a useful way of doing it, as you can save your progress and go back to it to make changes or add things as you remember them. If you do fill it in electronically, note that you still need to print it off so you can sign it. Alternatively, you can print off a copy, or ask for a form to be sent to you, and fill it in by hand. If you do request a form to be sent to you, it will include a Freepost envelope, which can be useful if you are sending lots of supporting evidence.
- If you do fill it in by hand, try to keep your writing legible, but don’t worry too much about spelling or writing in complete sentences. If you make a mistake, cross it out rather than using correction fluid.
- Look at all the most recent reports you have about your child and read them through. They can often help you to summarise your child’s needs and explain them on the form.
- Tick boxes on every page, but don’t bother filling in pages that aren’t relevant. Fill the box if you have plenty to say, and if you run out of space you can continue on additional sheets of paper. Make sure that you write your child’s name and date of birth on any extra sheets.
- Don’t underestimate the help your child needs; think through the extra sort of assistance they need compared with other children of the same age, as this is what they are assessed against.

‘It’s hard doing the form. It made me focus on all the things Henry can’t do. But I needed to be realistic and honest about all the challenges we face, to get the help we need.’

- As you fill in each page, describe what happens at mealtimes, bathtime, bedtime, at the shops, on public transport and so on. Say exactly what help or supervision you give. Say what would happen if your child didn’t get this help.
• It can help to give examples of how a child of the same age, or a sibling of a similar age, who does not have SEND would cope in the same situation. Would they manage the same task without the support your child needs? Perhaps they are able to do this task completely independently.
• It is also helpful to include examples of what happened when your child did not get help, or did not have the right level of support, as this can help the person assessing your claim to fully understand the challenges you and your child face.
• Don’t forget about glasses, hearing aids and other important pieces of equipment. They can be costly to repair, or replace. If your child routinely breaks or loses these items, make sure you say so on the form.
• Write about the bad days, even if some of what you say feels very hard to share. If you gloss over difficult times you can guarantee your child’s behaviour will deteriorate the day after you send in the form. On the other hand don’t waste space detailing how amazingly talented your child is at drawing. The claim assessor wants to know what the difficulties are, so this should be what you focus on!
• Remember, the claim needs to be strong enough to convince someone who has never met your child. Read it back to yourself. Is there anything you haven’t said? What you read may seem repetitive, don’t worry, it’s meant to be. The Department for Work and Pensions (DWP) will be looking for common threads running through your claim.

How others can support your DLA claim

The DWP will also want evidence from other people who know your child, so be prepared. Check that all professionals whose details you include know you are claiming as the DWP may contact them. GPs are very often contacted but may not know as much about your child as consultants, so it may be worth making an appointment to put them in the picture. The DWP will usually contact your child’s school, too.
Get a supporting statement from a professional who really knows your child well. Whoever you choose must say how much more care or supervision your child needs and why. It’s not enough just to give a diagnosis, every disability impacts differently on individual children. If the professional has only seen your child in a clinic or at school, make sure they don’t have to guess how things are at home; ask them to read what you have written, or give them a summary of the main points you would like them to include in their statement.

Getting supporting advice for problems at night can be difficult, so keep a diary for a week or two. Show it to your GP or your child’s teacher and include it with the claim. It helps if others are able to say that you report broken nights. So if you have asked your GP for help with tiredness or your child’s disturbed nights, or if your child falls asleep or is irritable at school and their teacher can link this to your reports of broken sleep, ask them to include this in their advice.

Don’t rely on a professional to fill in their part and send it off, as it’s unlikely to be given top priority. Ask for it back by a particular date and make an effort to drop it off and pick it up yourself. Don’t trust the post; this is your only copy and you’ve invested a lot of time on it.

If at all possible, send supplementary evidence that supports what you are saying. So for example you could include copies of medical reports, speech and language assessments, psychological advices and your child’s EHC Plan (or a Statement of SEN if you are yet to transfer), as they help to build a picture of your child. However, do remember that the DWP will not return these reports, so always ensure that you send photocopies rather than original documents.

You should also make a copy of everything else you send, especially if you have filled the out by hand, so that you have a record of what was written. Keep the copies in a safe place; you will need to refer to them if you want a decision looked at again and when the claim is reviewed or if the original gets lost in the post.
To make sure that your claim arrives safely, consider sending paperwork by special delivery. Doing this is expensive but it’s worth the peace of mind. You get a receipt, the claim can be tracked, and the DWP has to sign to say they’ve received it. If you hand a claim into a Jobcentre Plus, ask for a receipt.

**Getting support with DLA forms**

West Sussex County Council runs a benefits advice service for families or carers of children and young people with SEND. It 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 you can email: robert.hayes@westsussex.gov.uk.

Reaching Families has produced a fact sheet on DLA, which can be downloaded at: www.reachingfamilies.org.uk/factsheets.htm

Many other disability organisations offer useful advice about claiming DLA for children and young people with specific illnesses or disabilities. Their websites can be good places to visit, especially if your child’s needs are just emerging. Many of these groups are listed at the back of this book.

Many of us find filling in the DLA form a rather depressing experience, because you have to concentrate on what our child can’t do rather than what they can. So when you’ve finished, make sure you spend some time focusing on the positives: enjoy the things your child can do and celebrate their successes.

**What to do if your DLA claim is unsuccessful**

If your application for DLA is turned down, don’t give up. You can request a ‘Mandatory Reconsideration’, which must be made within a month of the date on the decision letter. You must have this done before you can proceed to an appeal and you will need to include a copy of the Mandatory Reconsideration with the appeal.
If you think you should be paid DLA at a higher rate than the one offered, you also have the right to ask for a review. This sort of review is called a ‘revision’. You can also ask for a review if your child is receiving the benefit at a lower rate and his or her condition alters and they need more help. Where a decision was correct at the time but circumstances have changed, the review is called a ‘supercession’.

It’s important to seek advice before asking for a decision to be looked at again. If you are unsuccessful, you can still appeal to an independent tribunal. If you don’t want to attend in person, you can submit an appeal in writing, or send a representative to act on your child’s behalf. However, it is worth attending if you can, as paper appeals tend to be less successful than those made in person. The form you need to appeal is called SSCS1 notice of appeal, which can be downloaded from: www.gov.uk. Alternatively, call the DWP on: 0345 712 3456 to ask for a hard copy to be sent to you.

There are time limits for reviews and appeals, so always get advice as quickly as possible. If you are on a very low income your local Citizen’s Advice Bureau may be able to help you with an appeal.

**Carer’s Allowance (CA)**

Carer’s 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 £116 a week after deductions (tax, National Insurance and other allowable deductions). This
amount is revised every April and is correct for the year 2017/18. 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 DLA, 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 Income Support (IS) because although CA is deducted from Income Support, claiming it protects your pension and makes you eligible for a Carer’s Premium. This increases the amount of IS you will get, so overall you will be better off.

How do I claim Carer’s Allowance?

The process for claiming CA is simple and quick. Call the Carer’s Allowance Unit on 0345 608 4321 or text on 0345 604 5312 for a claim pack, or claim online at: www.gov.uk/carers-allowance.

The online format takes account of your answers and skips irrelevant questions. You are sent a paper copy to sign and return. The claim pack is simple and easy to understand. You are guided to relevant pages and it only takes a few minutes to complete. You can make a claim when you apply for DLA and, as long as you meet the qualifying criteria, CA will be paid as soon as an award for DLA is made. Claims can be backdated up to three months, so you can wait and make a claim for CA once your child’s award for DLA is agreed.

If your child’s claim for DLA is turned down, or they are only awarded the low rate of the care component, apply for CA as soon as you can, while you challenge that decision. This ensures that your backdated CA is safe if the decision is revised.

What is Child Tax Credit (CTC)?

Child Tax Credit (CTC) is designed to help families with dependent children. If you are on a low or middle income you are likely to be entitled. You can claim for any children under 16 as long as you are responsible for them and
they usually live with you. It’s also possible to claim for children aged up to 20 if they are in full-time education, studying up to A Level (or equivalent standard) or they are in unpaid, work-based training. This includes children who are away at school in term time.

If you have a child who gets any rate of DLA, whether this is for care or mobility, the CTC you claim will include an extra Disabled Child Element. If your child gets DLA at the high rate for personal care, any CTC will include an additional severely disabled child element. These credits are in addition to all the tax credits available to other families.

‘The extra tax credits meant I could cut down my hours and spend more time with the kids.’

CTC is more generous than other benefits. Maintenance payments, fostering and adoption allowances and most other benefits, including Social Fund payments, are disregarded as income when HM Revenue and Customs (HMRC) calculate your entitlement. Student loans are also disregarded, as are any student grants relating to dependent children, books, travel or equipment.

Carer’s Allowance is counted as income though, so be sure to say if you are claiming it. If your child’s entitlement to DLA changes, tell HMRC as soon as possible.

If you’ve only just found out about Tax Credits and your child has been getting DLA for some time, it’s worth telling HMRC that you may have been entitled to Tax Credits and giving details. CTC has more flexibility than other benefits to look retrospectively at your entitlement. If your child’s entitlement to DLA changes, this may make a significant difference to your child tax credit award, so it’s in your interests to tell the Inland Revenue about this as soon as possible.

How do I get CTC?

Telephone HMRC Tax Credit Helpline on: 0345 300 3900, textphone: 0345 300 3909.
Parental leave

Parental leave is unpaid. But it gives parents the right to time off work to look after their children and is more generous for parents of disabled children. It’s even more important to strike a better balance between work and home when you have a child with SEND, and in order to give more time to family commitments.

Employers and employees can agree their own terms and conditions for parental leave. It’s worth checking your own contract; it may be more generous than employers are legally required to offer. For example, it may include a few days’ paid parental leave.

If there is no mention of parental leave in your employment contract, the legal minimum automatically applies. This is called the ‘Fallback Scheme’. For every child in your family getting DLA, each parent can take up to 18 weeks’ parental leave.

Although parents can only take up to four weeks a year, the leave can be taken on a daily basis, rather than a week at a time and it can be taken at any time up until your child’s 18th birthday. This is a real help if you’ve ever felt uncomfortable asking for time off to get your child to medical appointments, to attend Annual Reviews, or lovely things like school plays and concerts.

To take parental leave, you must have worked for your employer for at least a year. You must also give your employer at least 21 days notice, in writing. In some circumstances your employer can postpone your leave for up to six months, if they feel your absence would significantly disrupt their business. If this happens to you, call the Working Families free legal helpline for advice on: 0300 012 0312.

Universal Credit

Universal Credit (UC) is a radical new approach to welfare benefits. It is an integrated means-tested benefit for people in or out of work. UC will replace many familiar benefits, and includes allowances for adults,
additions for children, childcare costs, limited capability for work, caring and most importantly housing costs.

Universal Credit has been launched in some parts of the country for all claimants. In other areas, including West Sussex, it has only been rolled out for single claimants to date. At some point, there will be no more new claims for Income Support, Income-based Job Seekers Allowance, income related Employment and Support Allowance, Tax Credits or housing benefit and anyone claiming these and reporting a change of circumstances or a break in their claim will be moved to Universal Credit.

Until Universal Credits have been introduced fully we cannot be sure about its impact locally, but it is likely that some families will be worse off. Information and advice on Universal Credits can be found at:

www.citizensadvice.org.uk
www.gov.uk
www.moneyadviceservice.org.uk
www.turn2us.org.uk.

Other benefits

The Family Fund: What is it?

The Family Fund is for families on low incomes who have children aged under 17 with severe disabilities or serious illnesses.

Many parents have found that the fund is a great help for one-off payments for specific things like washing machines, fridges, beds, outings and holidays in the UK, or even abroad. Eligibility depends on the family in question being in receipt of certain government benefits, such as Child Tax Credit, Income Support or Housing Benefit.

Although the fund considers most requests, they give priority to people whose social or financial needs are greatest. They cannot help fund equipment or services that are the responsibility of health or social services to provide. You cannot get help for a child who is in the care of the local authority.

How do I apply?

You can get an application form by calling the Family Fund on:
01904 550055, or you can apply at: www.familyfund.org.uk. You may want to ask a professional to support your Family Fund application.

When you apply, you will need to give details about your child and what help you need. The fund will ask for details of your income and savings, and may contact your consultant for more information on your child’s disability. The first time you apply, a family support worker will arrange to meet you and your child at home to get a better picture of your needs. The meeting is informal and sometimes they suggest things they help with that you may not have thought of.

**Discretionary Social Fund: What is it?**

The Social Fund award Community Care Grants, Budgeting Loans or Crisis Loans for needs that are hard to meet from weekly benefits. If you are on Income Support, you could get a loan or grant towards the cost of a specific piece of household equipment or furniture, or to visit someone in hospital.

It can be very hard to get money from the Social Fund; there is no legal entitlement, payments are discretionary and the budget limited. Always apply for a grant rather than a loan if you think you are eligible.

Although the loans are interest free, budgeting for repayments can be difficult. There are different eligibility rules for each sort of payment. You can find out more from your local Jobcentre Plus.

**The Local Assistance Network**

The Local Assistance Network (LAN) is run by West Sussex County Council together with other organisations. It provides short-term practical aid, such as food or furniture, to people who have no other way of getting assistance in a crisis. It is open to: people on benefits or a low income; those facing an unforeseen emergency that puts them or their family at risk; people who need help moving into or remaining in the community; those who live in West Sussex or are being resettled here.
Types of help include:

- food from foodbanks
- furniture from recycling schemes
- vouchers for personal and household goods, such as nappies, cooking equipment and clothes
- help with transport and fuel costs.

Information on organisations in your area can be found in the Local directory on page 176. You can also access the LAN via your local Children and Family Centre.

**Fares to hospital**

Parents can spend a small fortune getting to hospital, particularly if children need frequent treatment or can’t travel on buses or trains. Your hospital social worker or the consultant’s secretary should help you find out whether your child can get an ambulance, hospital car or help with taxi fares. When taking your child out of the area for treatment you might get help with travel costs. Ask your consultant to write to the Health Authority for you, making it clear that the journey is a necessary part of your child’s treatment and you should get it paid. The Family Fund will also consider requests for help with travel costs to and from hospital.

If you are on Income Support, income related Jobseeker’s or Employment and Support Allowance and for some people receiving tax credits, the Hospital Travel Cost Scheme can help with fares to hospital.

If you do not receive any of the above benefits but your income is very low, you may still be able to claim travel costs through the NHS Low Income Scheme.

For more information on both schemes go to: www.nhsbsa.nhs.uk/nhs-help-health-costs, or call: 0300 330 1343.

**Council Tax reduction for people with disabilities: What is it?**

If you’ve had to adapt your home especially for your disabled child, your council tax bill could be reduced to that of a house in the band immediately below
yours. If your house is already in the lowest band (A) you get a reduction of a sixth of your bill. The sort of adaptations that might make the difference are:

• Additional space for a wheelchair to be used indoors, such as widening doors and corridors, and/or removing partition walls.
• An extra room to meet special needs, such as a downstairs bathroom or toilet.

The Council Tax Discount Scheme: What is it?

If there are fewer than two adults resident at your home, you can get a discount on your council tax bill. This is worth 25 per cent if there is one adult. Where there are no applicable adults, a council tax exemption is granted. Not all adults are counted for council tax purposes. Young people aged 18 or over getting DLA at the middle or highest rate for care are disregarded. So it’s worth checking.

How do I get it?

Ring your local council tax office to make an application for a reduction in your council tax band or a discount on your bill. If you have missed out in the past, you can ask for either of these to be backdated to the date they first applied.

Motability

Families of disabled children who receive the higher rate mobility component of DLA (or PIP if over 16) can use it to buy or lease a car, or an electric wheelchair, through a scheme called ‘Motability’. To use it, your child must have at least 12 months of their DLA award left to run. For details of the schemes call Motability on: 0300 456 4566 or visit their website: www.motability.co.uk.

Charitable Grants

Some charitable organisations make grants for specific purposes like holidays or buying a special piece of equipment. We have included a directory of grantmakers at the back of this
book. However, there are bound to be more so if you know of any and would like to share them with us and other families, please let us know.

There is a knack to securing grants from charitable funders. The following are just a few tips when applying:

• Most grantmakers produce guidelines, often available online, detailing what they give to and just as importantly, what they don’t support. Make sure you read these guidelines carefully before applying.
• Remember that each funder has their own interests and, as a result, a one-size fits all application that you send to several grantmakers is bound to fail. Instead, tailor your application to suit the criteria of each funder.
• Avoid using jargon or technical language – grantmakers are notorious for their love of plain English.
• Ask another parent or perhaps a professional to read your application before you send it off. If they have trouble reading it then so might the grant-maker.
• Don’t be over-emotional or rage against injustice – state your case in detail and provide as much information as you can in support of the application.
• Explain what else you’ve done to try to secure the things your child needs, including requests made to statutory services.
• Even if it is not required include a supporting letter from a professional, for example, a doctor, social worker or teacher, whichever is the most appropriate.
• Try and make your application as presentable as possible. An attractive and easy to read application is more likely to be successful.
• Make sure you send everything the grantmaker requests. If you don’t your application might be delayed or, worse still, ignored.
• Remember that competition for grants is fierce. Many good applications are turned down simply because of demand – so make your application as strong as possible but don’t blame yourself if your first attempts are not successful.
Childcare Inclusion

West Sussex County Council provides advice, guidance and training for early years and childcare practitioners to enable children with additional needs to attend mainstream provision. The local advisory team helps practitioners to develop the expertise and to make the necessary adaptations to support the learning and development of children in their care. This may include visits to settings before a child has even arrived to ensure plans for their inclusion are in place.

Where appropriate, funding may be made available to settings in line with criteria to enable the needs of individual children to be met. Funding is also made available to supply mobility equipment where this is recommended by health professionals, to support the child’s inclusion.

Free Entitlement Funding

Parents or childcare practitioners interested in the support available should contact them through the Family Information Service. Free Entitlement funding is available for all three and four year olds and provides 15 hours per week (570 hours per year) of early education and care with Ofsted-registered providers. All parents can access these free hours, regardless of their circumstances and some two year olds are also eligible, including those in receipt of DLA.

In addition, from September 2017, the amount of free hours for some working families with three and four years olds may increase, depending on their individual circumstances. Some working parents may be able to claim an additional 15 hours of care, bringing their total allocation to 30 hours a week (1,140 hours per year).

For eligibility criteria, go to: www.westsussex.gov.uk/freechildcare. You can also find out more about childcare and benefits at: www.childcarechoices.gov.uk.
Disability Access Fund

From April 2017, the Disability Access Fund is available to three and four year olds who receive DLA and Free Entitlement Funding. Early years’ settings must identify children who are eligible. The setting can then apply for a one-off annual payment of £615 to help them to support the child and meet their individual needs. If your child is eligible, it is worth checking with your childcare setting to ensure that they have applied.

Tax-free Childcare

In 2017 the Government introduced Tax-free Childcare, whereby they will contribute 20 per cent towards childcare costs per child for under 12s, and 40 per cent for a child with a disability who is under 17. This scheme is run for parents who are working, including those who are self-employed. For more information about Tax-free Childcare and other ways to get help with childcare costs, go to: www.childcarechoices.gov.uk or www.westsussex.gov.uk/freechildcare.

Parents in full-time education

If you are in full-time education, you can apply for a Childcare Grant to help you if your disabled child is under 17 and you are eligible for student finance. For more information, go to: www.gov.uk/childcare-grant.

Personal budgets

A key focus of SEND reforms has been giving parents and children more involvement and control in decision-making, as well as more choice and flexibility in the way in which care and support is provided.

The Children and Families Act 2014 gives disabled children and young people the right to request a Personal Budget as part of an EHC plan.

A Personal Budget is an amount of money identified by the local authority to deliver parts of the provision set out in your child’s EHC Plan. It gives you the flexibility to choose which services and support to use in order to meet your child’s outcomes.
A Personal Budget is not the total amount of money available, as it does not include the cost of a school place or existing support provided by a school, such as additional learning support.

There are four ways in which a Personal Budget can be paid:

• As a Direct Payment, which you can use to arrange and pay for your child’s support yourself.
• As a ‘notional budget’ where the council uses your child’s Personal Budget to arrange the support on their behalf.
• As a ‘third party arrangement’, where funds are paid to another individual or organisation on behalf of the child and they manage the funds.
• Or you can opt for a combination of all three.

**Direct Payments**

If you decide that you want to receive your child’s Personal Budget as a Direct Payment, you can use it in a number of ways to meet the outcomes identified in their EHC Plan. For example, you may choose to employ someone, often known as a ‘Personal Assistant’ (PA) to care for your child, or buy into a local service, like a day nursery, an after-school club, holiday playscheme, or even a residential short break.

Unless there are exceptional circumstances you cannot use Direct Payments to employ a close relative who lives in your household, although you can use them to employ a relative who lives elsewhere.

Until a child is 18, parents can use Direct Payments to pay for and arrange services for their child. Young people over 16 can choose to take responsibility for their Direct Payments or share the responsibility with their parent if they are under 18.

Once a young person is 18, they can still nominate 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 child is assessed as needing support, they can’t be refused Direct Payments if you 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 have made you aware that Direct Payments are an option.

**Why choose Direct Payments?**

Direct Payments allow you to have choice and control over the support you receive in order to meet the outcomes that have been identified for your child.

Direct Payments give families greater flexibility, however you will have a more active role to play, which will include ensuring that money is used to meet the outcomes identified in the plan and providing bank statements and receipts to show how the money has been spent.

**Direct Payments in West Sussex**

If your child does not currently access any services and you think they may be entitled to some, ring the Multi-Agency Safeguarding Hub (MASH): on 01403 229900 and ask for an assessment. You can also complete an initial enquiry form online at: www.westsussex.gov.uk.

In West Sussex, Direct Payments for parents are managed by the local authority. You can find more information and support on Direct Payments and being an employer through Independent Lives, a user-led charity working with disabled people, people with care needs, and carers, to enable people to lead full, active and independent lives.

The charity is commissioned by the local authority to provide a range of services including Direct Payment information and advice, banking administration, payroll and recruitment solutions, so they can ensure that managing your child’s Direct Payments is simple and as stress-free as possible. For more information go to: www.independentlives.org or call their helpline on 0845 601 2399 or 01903 219482. Textphone: 01903 823173.
What should a Direct Payment cover?

A Direct Payment should be equivalent to the cost of the service run by the local authority. If there is no council service, you may have to negotiate over how much it would realistically cost to provide. Local authorities must make payments that cover the reasonable cost of buying a service to meet your family’s assessed needs. There should not be a standard ‘take it or leave it’ rate.

If you are planning to employ someone using Direct Payments, you will have legal obligations, so the amount you get must cover things like National Insurance (NI) payments, holiday and sick pay, as well as basic pay. It is also a legal requirement that you purchase employer’s liability insurance.

Remember, you really need to negotiate on the basis of a 57.6 week year, because anyone you employ has an entitlement to 5.6 weeks’ paid holiday and you will need someone else to cover while they are away, and they will need to be paid, too!

Finding the right people

Finding the best people to support your child is really important. They need to be suitably qualified and experienced in caring for children with SEND, but it is equally important that they are able to establish a good rapport with your child, and that he or she likes them, too! Some parents already have someone in mind who knows their child, or you may want to ask for recommendations from friends, but other parents advertise locally, or use a matching agency to help them.

If you are going to advertise for a PA, but you’re worried about the process, Independent Lives has lots of advice and resources, including templates for writing job descriptions, adverts, letters and interview questions. Find out more at: www.independentlives.org/recruiting-a-pa.

You can also find a list of OFSTED registered child-minders at: www.childcare.co.uk.
You probably won’t want to meet everyone who applies for a PA role, but once you have looked at all the applications you can draw up a short-list of people to meet. You will also need to act in accordance with equal opportunity legislation. You can find guidance on this at: www.independentlives.org/recruiting-a-pa.

**Being an employer**

Many parent carers feel a little daunted about being an employer, but it doesn’t need to be complicated. If you are concerned about it yourself, Independent Lives runs a payroll service. They can manage tax deductions, National Insurance contributions, holiday and sick pay and will provide you with a pay slip for your employee every month. This services does cost extra but will be allowed for in the Direct Payments you receive. For more information call: 0845 601 2399, textphone: 01903 823173 or go to: www.independentlives.org.

If you would prefer to run payroll yourself you can do this using HMRC’s free payroll software ‘Basic PAYE tools’, which can be downloaded online at: www.gov.uk/basic-paye-tools.

Keeping track of how you spend the money doesn’t need to be a burden, either. You will need to open a bank account just for Direct Payments. The law says that local authorities must check that the money you are given is used for what has been agreed. So using Direct Payments does require you to keep accounts and records of how the money is spent. But you should not have to make weekly or even monthly returns if this doesn’t make sense in your circumstances.

**Where to look for more help with benefits**

Locally, in the voluntary and community sector, the Citizen’s Advice Bureau (CAB) offers information, advice and support to claim disability related benefits. Contact information for your CAB can be found in the Local directory at the back of this book.
You can also speak to West Sussex County Council’s benefits advisor, Robert Hayes. To arrange an appointment with him, email your child’s name, age and your contact information to: robert.hayes@westsussex.gov.uk. Alternatively, call him on: 0330 222 2569, or 07850 240874.

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.

What happens when my child turns 16?

Once a disabled young person claiming DLA reaches the age of 16, they will be invited to apply for Personal Independence Payment (PIP).

Other benefits that you receive may also be affected, as your young person will be able to claim some in their own right.

It is advisable therefore to plan ahead for this before your child reaches 16, so that you can work out exactly how this will affect your income and make informed decisions to protect your family’s finances.

You can find out more about transition to adulthood and how this might affect your family’s benefits in chapter 6 of our partner title, Making Sense of Adult Life. Parent carers can order a free copy from our website, or download the chapters as PDF files. For more go to: www.reachingfamilies.org.uk.
When your child is diagnosed with a condition, it is likely that you will find that you have to juggle many appointments with different health professionals and services. Sometimes managing them and the paperwork can feel like a full-time job in itself.

Specialists tend to concentrate on just one area of your child’s condition. For example, speech therapists focus on communication and/or eating; physiotherapists on movement; so you will find that you may see a range of people in different departments, or even different centres.

However, while they are the medical experts, it is important to remember that as the parent you are also an expert on your child. You spend every day with him or her, you know what treatments are being given and you know how they affect your child. You are probably the one constant figure in your child’s care, and you understand him or her better than anyone else. With this unique knowledge, you should expect to be treated by professionals as a respected and valued partner in all aspects of your child’s care.

‘Every child with Down Syndrome is going to be different from every other, every autistic child is different from every other. How does a professional know exactly where your child’s strengths and weaknesses are, or what exactly their comprehension level is? Tell them.’

You may find it useful to use your child’s Personal Child Health Record or red book to make notes about key episodes in your child’s health. You can get extra pages for your child from your health visitor. During your child’s early years, contacts with health professionals, both in hospital and in the community, should
also be recorded in the red book and it helps if you take it to appointments so that you have a full record of who is involved with your child.

Managing medical appointments

‘After our first appointment my head was spinning. I couldn’t remember a lot of what was said. So I got a notebook. Now, a few days before each appointment I start a list of things I want to talk about, then I add stuff as I think of it. In the appointment I make brief notes and fill in the details when I get home. I also use it if I speak to anyone on the phone. It’s incredibly useful to have a record of what was said, who I talked to and when.’

Assessments, appointments, consultations, or visits by health professionals can feel stressful, worrying and tiring, particularly if you are given upsetting news. Once you are in an appointment, it can be difficult to remember everything you wanted to ask, particularly if you are trying to keep an eye on your child, too. Sometimes it is only once you have left that you realise you have forgotten to ask something really important.

The coping question

Sometimes parents may say things are fine and they’re coping, even when it’s not true.

But 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 so they can try to help you.

How to be prepared

Taking a few minutes to prepare for each appointment can be useful to help you gather your thoughts and ensure you have remembered everything you want to cover. It can be helpful to make a list of what you want to discuss and questions to ask.

In the meeting note down the responses. It may take longer, but when you get home you’re more likely to have the information you need.
Tips for appointments

- Think ahead about the information you need from a consultation.
- Make a list of questions and take this with you. Make sure you have a pen so that you can take notes in the meeting!
- If your child finds new places challenging, it may help if you can prepare them before you go. Try to find an information leaflet or web page with photos of the place where the appointment will be held so they can see where they are going and the equipment they might see there.

Who’s who?

At first, you may feel confused by the abbreviations and unfamiliar jargon people use to describe services that your child may need to access, such as SALT (Speech and Language Therapy) and OT (Occupational Therapy), for example.

If you’re not familiar with the jargon being used, don’t be afraid to ask for an explanation, but this list of ‘who’s who’ in health should help you to navigate the services on offer.

Although it is long, it is not an exhaustive list. However, it will allow you to familiarise yourself with the names and roles of some of the services that are commonly involved with treating children.

**Audiologist or Clinical Scientist (Audiology):** clinicians who provide assessment, diagnosis and rehabilitation of hearing and balance problems. This includes interventions such as hearing aids which can reduce the barriers to communication created by hearing loss.

**Child and Adolescent Mental Health Service (CAMHS):** a multidisciplinary team of psychiatrists, therapists and others who specialise in helping children with mental health issues. You can be referred by your GP or other professionals.

**Children’s 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.

**Children’s Community Nursing Team**: provide out of hospital care for children who are ill or require nursing to enable them to stay at home, school or in another community setting. This includes: babies, children and young people who have a long term health condition; complex health needs and disability, including requiring continuing care; a life-limiting or life-threatening illness, including palliative and end of life care. The team provides practical advice and support to families and carers.

**Clinical Child Psychologists**: diagnose, assess and treat emotional and behavioural difficulties and may offer counselling for families in difficulty.

**Community Dentists**: sometimes children with disabilities or other conditions, such as extreme anxiety, are referred to a community dental clinic, where the dentists have additional skills in treating them. They may also make home visits when appropriate.

**Community Mental Health Workers**: community-based service to help children with emotional or mental health issues. Can work with children and families at home or in school. Any service that knows you and your child can refer you. Community Mental Health Workers will refer on to CAMHS if they think this is more appropriate.

**Community Paediatrician/Community Child Health Doctors**: work at Child Development Centres (CDCs), in child health clinics or in schools. They may also make home visits.

**Community Services Pharmacists**: have a responsibility for ensuring that pharmacy services are provided to community healthcare units. They play an important role in liaising between various agencies that provide care.
Consultant: senior doctors who have specialist qualifications in a particular area of medicine or surgery.

Consultant Community Paediatricians: have a special interest in developmental and learning difficulties and co-ordinate care of the children who have them.

Consultant in Rehabilitation Medicine: specialist doctors who often lead a multi-disciplinary team to help people with complex disabilities. They work on treating and preventing symptoms and complications, and also have specialist expertise in areas such as wheelchairs and orthotics and assistive technologies.

Dietician: healthcare professional who advise and work with people with special dietary needs in order to promote well-being and prevent nutrition-related problems.

General Practitioners (GPs): family doctors.

Health Visitors: mainly work with children under five. They may keep in touch with parents of older children with SEND, but you may have to ask. They offer development reviews on children at various stages and can be the first to spot a problem that needs referring to a specialist. They often know about local services, support groups and benefits. They can support applications for respite care, re-housing, adaptations to your home, and so on. See also Paediatric Liaison and Specialist Health Visitors.

Occupational Therapists (OTs): help children to develop everyday skills such as feeding themselves, getting dressed, classroom-related tasks and playing. They will assess and/or treat children at an appropriate setting in the community such as your home, educational setting, or local Child Development Centre, offering advice and/or treatment as well as recommending special equipment.

Ophthalmologist: doctor who specialises in the medical and surgical management of conditions of the eye.
Opticians: if there are reasons why it’s difficult to take your child to the opticians, you can ask any optician for a home visit. Glasses for children are no longer free, but there is a voucher scheme to help toward the cost. Ask the optician for details.

Optometrist: healthcare professional who performs eye tests and prescribes corrective lenses or glasses to those who need them.

Orthoptist – investigate, diagnose and treat difficulties with binocular vision and problems with eye movement. This includes double vision, reduced vision and eye misalignments (squints).

Orthotist: qualified to design and fit ‘orthosis‘ – surgical appliances like braces, callipers, footwear, and so on. Orthotics deals with the support and bracing of weak joints or muscles.

Paediatric Liaison Health Visitors: based at Chichester and Worthing Hospitals, they are trained children’s nurses with specialist knowledge of children’s conditions. They can supply community health visitors with detailed information relating to your child’s condition.

Paediatricians: doctors who have specialist qualifications in all aspects of children’s health and development.

Physiotherapists: work with children and their families to help develop children’s movement skills, function and mobility. They do this by offering advice and activities to help encourage important skills such as rolling, sitting, crawling and walking, as well as encouraging active play to help develop strength and balance.

Psychiatrists: doctors with specialist qualifications in diagnosing and treating people with mental health problems. Child Psychiatrists work with children and young people.

School Nurses: work in special and mainstream schools. They undertake health assessments and offer advice and support on a number of health-related issues to parents, carers and teaching
staff. When necessary, with parental consent, they can refer children to other NHS or partner services. School nurses in special schools may also be involved in the health care of children.

**Specialist Health Visitors** : the specialist health visiting service is for children with complex and additional needs and their families. They ensure that correct support is given to the child by sign-posting and sometimes handling referrals to other services. They can also help with sleep and behavioural issues. The service normally covers children aged from birth to eight years, however exceptions can be made for children over this age. It can be accessed in many ways; via early years’ settings (such as pre-schools and schools), GP’s, Child Development Centres, or parents can self-refer direct to their local health visiting team.

**Speech and Language Therapists (SALT):** diagnose and treat problems with understanding, communicating and speaking. They can also help with swallowing and eating difficulties. Speech and Language Therapists can play an important role in providing assessment, intervention, support and training.

**Referrals**

Your GP or health visitor is usually the person to ask if you think your child would benefit from seeing a specialist health professional.

Occasionally, you may be referred by another professional, such as a social worker or educational psychologist. Some of the specialists listed above also accept self-referrals, or may at least provide advice over the telephone.

If you have to wait a long time for an appointment and things get worse, go back to your GP and ask them to try to bring your appointment forward.

**Your doctor (GP)**

Even if most of your child’s treatment is at a clinic, it’s important to have a good relationship with your GP, as your child will inevitably have common childhood illnesses, which will usually be dealt with at the practice.
Most GPs will only have a few patients with SEND on their list. If your child has a very rare condition, it may be the first time the GP has seen someone with it. A good GP will appreciate all the information that you can give, and the knowledge you have acquired about your child and their needs. Your GP can also be an ally if you’re trying to bring forward an hospital appointment or find respite care, so it is worth asking for their help.

As children get older, many will want to have a say in their care. Start practising when they are young and try to build a good relationship between your GP and child. Encourage your child to take part in appointments as much as possible, using their preferred method of communication.

Supporting your child in appointments will help him or her to develop the skills and confidence needed to play as active a role as possible in their adult healthcare choices. This may sound unnecessary, but when your child hits their mid-teens, he or she may want to see the GP independently. Once they are 18, as long as it is felt that they understand (also known as ‘having capacity’) you will have to take a step back, if this is what they want. So recognising this as a future possibility and giving your child the skills he or she will need is vital.

**Continuing care**

After diagnosis, children and young people remain under the care of paediatricians, who usually continue to see a child until they are 19 years old.

Many children are seen regularly by their local Child Development Centre, their local hospital, paediatricians, Chailey Heritage, special schools, local clinics or specialist centres further afield, such as in London hospitals.

Child Development Centres hold regular, specialised clinics and groups for young children with developmental difficulties. These are run by various health professionals offering ongoing assessment, support and therapy.
Chailey Heritage continues to offer a wide-ranging and highly specialised service for children up to the age of 19 who have complex needs.

Children with ongoing eye or ear problems might go for their regular checks to their local hospital’s Ear, Nose and Throat (ENT) department, or to the Royal Alexandra Hospital in Brighton for more detailed assessment.

Children with chronic asthma receive their care locally by consultants with a special interest in asthma and by tertiary consultants in London or Southampton. You will probably be given appointments to see the paediatrician or specialist at regular intervals, and they should write to your child’s GP each time to keep them informed about progress and treatment.

Children aged four years or over may benefit from the Continence Service, which helps with the management of bowel and bladder conditions.

Children requiring significant support with their emotional or behavioural needs will be seen by the Child and Adolescent Mental Health Services (CAMHS), which has teams in Chichester, East Grinstead, Haywards Heath, Horsham, and Worthing. There is a waiting list, but urgent cases do take priority.

CAMHS may see existing patients until they’re 19 years of age.

Children in need of psychiatric inpatient facilities go to Chalk Hill in Haywards Heath for this type of care.

**Education Health Care Plans (EHC Plans)**

For information on EHC Plans, go to Chapter 7, Education.

**Rehabilitation services**

The Sussex Rehabilitation Centre is situated at Brighton Hospital and can provide artificial limbs and wheelchairs. More complex problems are referred on to the Rehabilitation Engineering Unit at Chailey Clinical Services.
There is also a special unit, Chailey Rehabilitation Service, for children with acquired brain injuries. They may go there straight from acute care at a hospital, and each child has a completely individualised programme.

**Transition to adult 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.

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.

Health services are responsible for identifying whether a young person is likely to have ongoing healthcare needs and to make sure these needs are met when they become an adult. They should ensure there’s a clear process for transferring responsibility and information, but parental involvement can also help this to go smoothly.

**Hospital treatment**

**Going to A&E**

There are Accident and Emergency (A&E) departments at: Royal Sussex County Hospital in Brighton; St Richard’s Hospital in Chichester; the Princess Royal Hospital in Haywards Heath; East Surrey Hospital in Redhill; and Worthing Hospital.

You can’t assume that A&E will always have qualified paediatric nurses on duty, and, if you are in another part of the country, your child’s medical records will not be readily available. In this type of situation, parents have a vital role to play in helping staff to treat their child.
‘I think you can help the Health Service to be more useful to you. We were up at the A&E department three weeks running one time, and I always find if you’re in a place like that where you might have to wait a long time, it’s no use just sitting there waiting and hoping your child won’t have a massive tantrum. You’ve got to be upfront and you’ve got to tell them exactly why your child’s got to be seen next. They were always absolutely brilliant and got her in there really fast.’

In-patient treatment

In our area, most children who need hospital treatment go to Chichester, Redhill or Worthing Hospital or, sometimes the Royal Alexandra Hospital in Brighton.

Sometimes, children are sent to specialist centres where they may spend some time before returning to their local hospital for ongoing care. London hospitals they may be referred to include: St George’s Hospital; the Evelina (part of St Thomas’ Hospital); or Great Ormond Street. Alternatively they may be sent to Southampton.

Children who are treated locally may have been seen by specialists at your local Child Development Centre. Staff from each centre have plenty of contact with each other, and many of the nurses have years of experience of the conditions treated at your CDC. However, everything you can do to share your knowledge and help communication will make things easier for your child.

‘You have to be very specific and say, “Look, she really is like this,” and, “No, she can’t do this,” and, “If you’re calm, she’ll be calm,” or whatever. Be upfront so that they know the problems – spell it out!’

Preparing for a hospital stay

• Many hospitals have information or materials, such as websites or books to help prepare your child.

• Hospitals may also have specialist staff who are trained to help children and young people to prepare.

• Ask about staying with your child in hospital. Children have the right to have their parents with them in hospital.
• To help you share important information about your child with hospital staff so they can understand their needs. Many hospitals now have a ‘passport’ for you to complete. You can find a blank template to print out and fill in at: www.sussexcommunity.nhs.uk/downloads/services/learning_dis_health/ldhft-hospital-passport.pdf

During the stay

• As well as the ‘passport’, detailing your child’s needs, it may be worth having key information such as ‘Hayley uses signs to communicate’, on a piece of paper that can be taped above your child’s bed for all staff to see.

• If it is important that staff ask closed questions, use simple phrases and ‘listen on all channels’, make sure you have explained this to them.

• If your child doesn’t use speech, you may need to teach staff some signs or how to use your child’s communication book.

• You can read your child better than anyone else. If you notice changes in body language, mood or pallor, this could indicate they are in pain, too hot or too cold, so be sure to alert staff immediately.

• Be sure to tell everyone about any medication your child takes; some lower blood pressure, and new medications may be incompatible.

• If your child is on regular medication, check who will administer this while they are in hospital. If you plan to do it, you will need to sign to authorise this. If hospital staff are going to administer meds, expect them to be taken away from you.

• Don’t assume staff know everything about your child’s condition, or that information has been shared between departments.

• If your child is having an operation, ask if they can be first on the theatre list if you think they may find it hard to cope being ‘nil by mouth’ (going without food or drink), or if they are likely to be distressed or confused.
• Help your child stay in touch with friends and with school by email, it will make returning to school easier if they miss a lot. Most hospitals now have public Wi-Fi so ask about this before their stay.

• Many hospitals have a teaching service that can help your child to keep up to date with their studies.

‘It is your child, it is not the doctor’s child and if you don’t like the way they’re bandaging him, or they’re doing something that you know will upset your child – even though all the other children with that syndrome are bandaged in that way – you say so, you negotiate.’

Leaving hospital

Ask about discharge planning and assessments of need as early as possible. Agreeing who is responsible for funding nursing care, training, equipment, aids and adaptations at home can be complex and take time so it’s worth checking that your child’s community nursing team are anticipating their needs early on, or your child’s stay in hospital may be longer than either of you would wish. Each hospital has its own discharge policy. Ask to see this before your stay if possible. And don’t forget to ask about an assessment of your needs as a carer too. For more on this, go to page 122.

Complementary medicine

Complementary medicine includes treatments like osteopathy, acupuncture, homeopathy, massage and aromatherapy.

Some parents find these useful for themselves or their child. But it can be difficult to find out practitioner’s qualifications. Other parents are often the best source of information, although some GPs have an interest in this field. Many of the established types have a governing body that can advise on finding qualified practitioners.

Occasionally, some complementary medicines are available under the NHS but usually it has to be paid for privately, although some practitioners will offer treatment
on a sliding-scale of payment. For example, The Dolphin House Children’s Clinic in Brighton, which offers a variety of natural therapies, works in this way.

The Belltree Music Therapy Centre in Brighton is a professional music therapy service. Private clients can refer themselves to the service or referrals may be made by professionals such as paediatricians, speech and language therapists, social workers, and psychologists.

Clients who self-refer will be charged for an initial assessment and for any subsequent treatments thereafter.

**When there’s a problem**

**Patient Advice and Liaison Service (PALS)**

PALS has been set up by NHS Trusts to provide advice and information about health and related services. They are a useful source of local and national information and, if they do not have the answers, will find the information or the right person to speak to.

PALS also help if you have concerns about local NHS care. PALS staff aim to resolve concerns informally through liaison with the relevant NHS staff. PALS will also advise on making a complaint, what the process involves, and signpost you to the NHS Complaints and Advocacy Service, which is independent of the NHS.

**Healthwatch**

This is a 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 delivered by the Citizen’s Advice Bureau. They will listen to your concerns, suggestions, queries and comments on health services. If need be they can help to sort out problems on your behalf.
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. Any Citizen’s Advice Bureau in West Sussex can refer you to ICAS. Alternatively you can contact them on 0300 303 8536, or by email at: icas@westsussexcab.org.uk

Complaints about healthcare

If you are unable to resolve your concerns by using PALS or ICAS, you can complain directly to the Parliamentary and Health Service Ombudsman. You can find out more about the ombudsman at: www.ombudsman.org.uk.

The process has two clear stages: the complainant’s case is either resolved locally or taken forward to the Ombudsman. PALS can advise about taking complaints to the Ombudsman.

Compensation

If you believe your child is the victim of a medical accident and could be entitled to financial compensation, you can take legal action against the person or establishment concerned. A good financial settlement could make a huge difference to a child’s long-term future, and to the peace of mind of parents and siblings. However, you also need to be aware of the possible drawbacks. You could speak to PALS first to look at other ways of resolving the issue.

Lawsuits can be very expensive, and unless you win, you will not get your costs paid. Legal Aid is unlikely to be available. The process can take a very long time, sometimes years. You will need plenty of stamina and, above all, good legal advice.

If you do decide on legal action, you can get free preliminary advice from Action for Victims of Medical Accidents (AVMA). They can tell you whether your case is worth pursuing and can also suggest a good solicitor.
Education is a big part of family life for many years. If your child has SEND, there can be additional anxieties around finding the right placement for him or her and ensuring that they have the correct support in place to help them to learn and achieve the best possible educational outcomes.

Some of us know from birth that our children will need additional support with their education, but for many families, their child’s additional needs will only become apparent once their journey through the education system has begun.

This chapter will outline the types of support available to children with SEND and will also give you tips and advice on choosing the right type of setting for your child’s individual needs. If your child is in secondary school and you are considering their options for Year 10 and beyond, you will find it useful to refer to our companion guide, *Making Sense of Adult Life*, which outlines the options open to our children up to Year 13 and beyond. Copies are free to parent carers and can be ordered from our website: www.reachingfamilies.org.uk.

**Educational support for very young children**

Most children under two can benefit from the facilities available for all very young children, such as parent and toddler groups and other activities available at children and family centres, music groups or soft play sessions (see Chapter 9 for more on this).

**Early Years Hubs**

Eight of West Sussex Children and Family Centres have Early Years Hubs, which offer additional...
services, advice and activities specifically for children with SEND.

Each hub runs ‘Play and Learn Plus’ sessions and some offer the chance for your child to access sensory areas and sensory toys. Sessions are also an opportunity for you to meet other parent carers. All hubs are wheelchair accessible and some also have hearing loops.

The hubs are based at: Bognor Nursery School and CFC; Boundstone Nursery School and CFC (Lancing); Chichester Nursery School and CFC; Durrington CFC; East Preston CFC; Horsham Nursery School and CFC; Langley Green CFC (Crawley); and Sidney West CFC (Burgess Hill). For contact information, see the Essential contacts, page 155.

Dame Vera Lynn Children’s Charity (DVLCC)

Based in Cuckfield, West Sussex, the charity offers an early intervention service for families with children aged from birth to five years with cerebral palsy and other motor learning disabilities.

The service follows the principles of Conductive Education and Early Years Foundation Stage and is delivered in partnership with parents to educate and help their child develop physically, socially and emotionally, forming the bedrock of the independence they can achieve later in life.

Messy play and sensory play are incorporated into sessions and additional services such as music therapy and swimming sessions are also offered to families. Full details and a programme of events can be found on the website: www.dvlcc.org.uk.

Portage

The Portage service is a self-help home teaching scheme for parents of very young children with significant support needs, from birth (some children are referred later as their needs are identified). There are five portage projects in West Sussex: Chichester; Crawley and East Grinstead; Horsham, Mid Sussex; and Worthing. Each is responsible to the county council. A trained
Portage Home Visitor comes to your home weekly, or fortnightly, for an hour. Together you work on focused activities with your child towards a goal which is directed by yourself. New skills are often acquired in small steps and your Portage Home Visitor will help your child move forward to reach them. Portage Home Visitors may also be able to support you at meetings with professionals or with visits to nursery and school settings when considering a school for your child. The service is free to families and is supervised by an Educational Psychologist.

Parents can be referred by any health professional they see. They can also self-refer to this service.

‘Portage has helped me become more positive about my child and her development. Celia herself is a lot more responsive to everything and really enjoys the activities.’

Family Support

This is a West Sussex service that provides personalised support, including home visiting, for families with children and young people aged up to 19 (25 for young people with SEND). Support workers will help parents by discussing strategies and solutions to everyday family issues and introduce you to local family activities.

If you are concerned about your child’s development, you can raise your concerns and get advice and support for your child. If it is determined that they need extra support an Early Help Plan will be drawn up for them. To find out more, speak to your local Children and Family Centre (see Essential contacts for details) or your health visitor, GP, midwife or pre-school. Family Support is one of several services which have been brought together under the umbrella of ‘Integrated Prevention and Earliest Help’ (IPEH) within WSCC – you can find out more about IPEH on page 116.

Funding childcare

Many parents worry about funding childcare for their children. However, there are a number of schemes to help parents including Free
Entitlement Funding, which provides free hours of education and care for all three and four year olds and some two year olds in receipt of DLA. In 2017 the Government introduced Tax-free Childcare, a scheme that is run for working parents. For more on both schemes, go to Money Matters, page 58.

**Childcare inclusion**

West Sussex County Council provides advice, guidance and training for early years and childcare practitioners to enable children with additional needs to attend mainstream provision. The local advisory team helps practitioners to develop the expertise and to make the necessary adaptations to support the learning and development of children in their care. This may include visits to settings before a child starts to ensure plans for their inclusion are in place.

Where appropriate, funding may be made available to settings in line with criteria to enable the needs of individual children to be met. Funding is also made available to supply mobility equipment where this is recommended by health professionals, to support the child’s inclusion.

From April 2017, there is a new Disability Access Fund for three and four year olds who receive DLA and Free Entitlement Funding. Early years’ settings must identify children who are eligible. They can then apply for a one-off annual payment of £615 to help them to support the child and meet their individual needs.

**Early Years Planning and Review Meetings (EYPARMs)**

If it has been identified that your child has, or may have, SEND he or she may be referred for review at an Early Years Planning and Review Meeting (EYPARM).

These ensure that there is appropriate discussion, planning, review and if necessary further assessment for children aged from birth to four who are likely to require additional support within their pre-school and school setting.
Requests for a child to be discussed may come from a range of professionals working in health services or education. Children are only discussed when parents give signed permission for a discussion to take place. In order to review your child, the views of those who work with you and your child will be sought. You will also receive a Parent/Carer pack to fill in so that your views can be taken into consideration.

There are currently two pathways for children with SEND. Pathway 1 is for children with complex needs who have a high level of need in several developmental areas. Pathway 2 is for children with additional needs who are likely to need extra support within their educational setting.

Who will be present at the meeting?

The EYPARM is a meeting that brings together professionals such as paediatricians, speech and language therapists, educational psychologists, the Early Years Consultant, Portage, representatives from local schools, and the EYPARM caseworker. The meeting is chaired by a team manager from the West Sussex Special Educational Needs Assessment Team (SENAT).

It’s worth noting that the professionals at the meeting may not have worked directly with your child. Therefore, it is important that the information they are given is as clear and as up-to-date as possible, so they can get a full picture of your child’s needs.

What might be discussed?

The EYPARM enables professionals to work together with families in the following ways:

- To identify and assess pre-school children’s SEN. This will include identifying children who may be considered for an EHC Needs Assessment of their special educational needs, and ensuring families are receiving the help and support they need.
- To help the co-ordination of services and support to families of young disabled children, using the Early Support Approach.
- To plan changes, for example from pre-school to school, to
ensure children with special educational needs receive the support they need throughout their early years.

- Written reports and information about your child will be gathered from the professionals working with you and your child to understand more about their needs.

What might happen after the meeting?

There are three possible outcomes from the meeting.

- **Request for further information.** The EYPARM may ask for further reports, assessments and information to discuss your child at a future meeting. This is most likely if your child is still very young.

- **Transition planning** when starting in a new Early Years setting or school. For many children the EYPARM will write to the school or Early Years setting working with your child and share the reports that have been gathered, outlining your child’s special educational needs. The EYPARM ask the professionals to work together with you to develop a written Transition Plan that will identify the help and support your child needs when they start in a new early years setting or school.

- **Involvement of an Educational Psychologist.** For a few children with more complex needs the EYPARM may ask an Educational Psychologist to meet with you and your child to understand more about your child’s special educational needs. The Educational Psychologist will contact you directly to arrange this. Early years children with significant and complex needs may be considered for an EHC Needs Assessment, following involvement from an Educational Psychologist, as part of the EYPARM process.

The majority of early years children with SEN are discussed through the EYPARM process. This means that should a child need to be considered for an EHC Needs Assessment a range of information and assessments has already been gathered about their individual strengths and needs, which then improves the quality of any subsequent EHC Needs Assessment that may be carried out.
Types of support in education

When your child is at preschool or school, their special educational needs can be supported in a number of ways. Most children will be helped through SEN Support, but some children with more complex needs are supported by an EHC Plan. This section will give you a brief overview of how these two types of support are put in place and how they help children.

SEN Support

If it has been identified that your child has special educational needs, your child’s keyworker in Early Years Settings, or school teacher will work with the Special Educational Needs Coordinator (SENCO) to gather information and find ways in which they can help your child. This is known as SEN Support.

Schools receive additional funding to support children with SEND who do not have EHC Plans. All settings should have a graduated approach to support with four action stages:

- Assess – analyse what the child’s needs are.
- Plan – work out what support to offer and how. This could be a special programme of work, particular equipment, time with a teaching assistant or teacher individually, or in a group. The planning should include the outcomes they expect to see from this support and a clear date for review.
- Do – the pre-school staff, class teacher or subject teachers put the plan into action, supported by the SENCO.
- Review – look at whether the support is working. Revise the plan in consultation with parents and the child.

The idea is that this cycle keeps happening for as long as the child needs SEN Support and, if they do not make the expected progress, things should intensify, perhaps by getting expert advice to assess in more detail, or by planning more or different support. This may involve getting the input of specialist services such as the Social Communication Team or Educational Psychology service, for example.
Parents should be involved at every stage. A record of the support to be given and the outcomes that support is meant to achieve should be shared with you. There are no specific rules about how a school should write this record but you must also get an annual report on your child and a face-to-face meeting at least three times a year.

Children can get a significant level of extra help on SEN Support which may include one-to-one help if it is needed in order for them to access education. SEN Support should also include planning for transition, such as when a child moves from nursery to primary school, for example, so that information is shared between the current and the new setting.

**Specialist services to support children’s learning**

The local authority has a number of specialist services, each offering expert advice and information to mainstream schools. Most of these services have a team of specialist teachers who can work directly with pupils, but usually concentrate on helping the school staff plan and deliver help for their pupils.

**Educational Psychology Service**

The Educational Psychology Service provides specialist advice around a child’s learning, well-being, and behaviour in their school placement. Referrals are made by the setting or the SEN Assessment Team.

**Sensory Support Team**

The Sensory Support Team works with children, families and schools to support and promote the inclusion of children with sensory needs: hearing; visual impairment; or multi-sensory impairment; in a range of settings.

The team provides a range of support including direct support to children in Early Years, providing advice and direct teaching in schools, supplying specialist technologies on an individual basis to improve access to the curriculum, providing specialist advice and support during assessments.
Referrals can be made by professionals or parents but the team advises that if parents have a concern about their child’s provision they should first discuss with their school or setting.

**Social Communication Team**

The Social Communication Team provides advice, training and support to schools to promote the educational, social and emotional development of children and young people with autism. With parental permission, the team accepts referrals from school SENCOs or head teachers.

**EHC Plans**

An Education, Health and Care Plan (EHC Plan) outlines a child’s special educational needs; what outcomes are wanted for the child and what special provision is needed to achieve these outcomes.

An EHC Plan is designed to be holistic, so it should also cover any health care and social care needs and outline provision to meet these needs and outcomes to work towards.

All local authorities have a legal duty to secure the special educational provision in an EHC Plan and the health service (usually the local clinical commissioning group) has a legal duty to arrange the specified health care provision.

**Does my child need an EHC Plan?**

Children can get significant amounts of help on the first level of help known as SEN Support at school or pre-school, so may not necessarily need an EHC Plan.

However, if your child has been getting help on SEN Support and does not seem to be making reasonable progress, or if your child is distressed about school or being excluded, it may be necessary to apply for an EHC Needs Assessment.

If it is felt that their current placement cannot meet their needs and your child would be best supported in an alternative setting such as a special school, unit or independent specialist provision, an EHC Plan will be required in order for them to
be placed there. However, in exceptional circumstances the local authority may agree to a child being placed in a special school while an EHC Needs Assessment is carried out.

The process of EHC Needs Assessment can shine a light on a child’s needs and bring together expert advice on this to give a fuller picture of how they need to be supported.

If it is decided that an EHC Plan is appropriate, this will set out their needs and the provision that should meet those needs in a document that also has some legal weight.

‘It has the reputation of being a long, drawn-out and daunting process full of complications. In practice it wasn’t half as bad as I expected. So grit your teeth and go for it!’

What about children without a diagnosis?

For many of us, it was only after our children started at playgroup or nursery that our children’s additional needs became apparent.

It is estimated by SWAN UK that as many as a third of children with SEND do not have a diagnosis, and for children with a learning disability this figure may be as high as fifty per cent. However, if their additional needs have been identified, they should still receive support at their educational setting.

The SEND Code of Practice sets out how early education settings and schools should identify and support children with special educational needs. For the majority of children, their additional needs can be met through SEN Support by staff within the setting. However, if it becomes apparent that your child’s needs are not being met through SEN Support, it may be suggested that an EHC Needs Assessment should be undertaken.

Some parents are under the impression that their child can only have an EHC Needs Assessment if they have a diagnosis, but this is not the case. The support a child is entitled to is based on need rather than a diagnosis.
Independent Support

Families whose children are undergoing an EHC Needs Assessment may benefit from the help of an Independent Supporter (IS), who can support parents and young people through the process.

In West Sussex, Independent Support is provided by Amaze. They can support families applying for an EHC Plan as well as those who are transferring over from a Statement of SEN. Young people aged between 16 and 25 years can also request an Independent Supporter.

Independent Supporters in West Sussex can support as follows:

- Explain the law, what is happening and how you should be involved.
- Help you to think about aspirations and outcomes for your child or young person.
- Support you to complete a parental or young person contribution book.
- Make sure you feel able to get your views across.
- Check you have information you need, including on the Local Offer and Personal Budgets.
- Go to EHC meetings with you.
- Look through reports with you to be sure you understand them fully.
- Ensure you know when you have choices or decisions to make about the EHC Plan, such as giving a preference for a school.
- Help you check through the EHC Plan to see if you are happy with it.

Parents and young people can call: 0300 123 7782, or email: is@amazebrighton.org.uk. Staff will offer advice and support over the phone and if they feel you need an Independent Supporter, they will match you up with one of the team.

‘My Independent Supporter was brilliant. She highlighted several things that I’d overlooked for my son’s EHC Plan and kept me calm when the stress started getting to me. I would’ve been lost without her!’

Requesting an EHC Needs Assessment

In this section, to keep things straightforward we will refer to
the education setting as ‘the school’, but the advice is also relevant for Early Years settings and Further Education.

The first step is to make a request to the local authority asking them to consider carrying out an EHC Needs Assessment of your child. It involves getting advice from a range of professionals, the parents, and child or young person, to decide if an EHC Plan is needed.

A request for an assessment can be made by the parent, young person (if they are over 16), or school. You can do this by contacting the West Sussex SENAT Team on: 0333 0142 90 or by emailing: SENSupportTeam@westsussex.gov.uk.

If you want to be sure this will be recognised as a formal request, you will need to put it in writing and refer to Section 36 (1) of the Children and Families Act 2014. This may sound daunting, but it is quite straightforward – if you are not sure what to write in the letter, you can go to the IPSEA website, where you will find letter templates that you can use, as well as many other useful resources to guide you through the EHC process. Go to: www.ipsea.org.uk.

You can also receive support from the West Sussex SEND Information, Advice and Support service (SEND IAS), see page 113 for details.

When the local authority receives the request, you will be given the name of a Planning Co-ordinator in the SEN team, who will be responsible for your child’s case. They will be your key point of contact, but do not do the decision-making. Decisions are made on the recommendation of a SEN panel that meets regularly. The panel ensures that the local authority makes fair and consistent decisions. Panel members include: a manager from the SEN team; a senior educational psychologist; representatives from schools and health care.

There are strict time limits about assessment and producing EHC Plans. The whole process from request to final plan should take
no more than 20 weeks. The LA has up to six weeks to make their decision about whether to go ahead with an EHC Needs Assessment. Again, you can find detailed resources, including a timeline of what should happen and when, on the IPSEA website. If you made the request for an assessment, the SEN team will contact the school for information. If the school made the request you will get a letter that asks for your views.

At this stage the local authority’s decision will be based on the information sent by you and the school. The SEND Code of Practice says the test is whether ‘it may be necessary for special educational provision to be made for the child in accordance with an EHC plan.’

The panel will first consider whether all possible support has been given through SEN Support by the school. So they may turn down a request for assessment if they feel that there is still more that the school could do in order to meet the child’s needs.

By the end of the six weeks, the LA will send you their decision. If they decide not to assess, you have a right to appeal. We have a section later about appeals to the SEN Tribunal, but before this happens, the SEN Assessment team should set up a meeting with the school and yourself to talk through the support that is currently being given. Often, there is room for negotiation and if this is the case it’s good to go over the evidence that was supplied, to check that there is nothing missing from the information on which the decision was based.

**How will an EHC Needs Assessment be carried out?**

If it is decided that an assessment should be carried out, the local authority must complete this by week 16 and, either issue a draft EHC Plan, or tell you they have decided not to issue one.

The aim of the EHC Needs Assessment is to look at the outcomes that will enable the child to progress in their learning and towards adult life, then work out what education, health and social
care provision is needed for the child to achieve these outcomes. To make the assessment the local authority must ask for advice and information from: parents or the young person if they are aged over 16; the school or education setting; health professionals involved with the child; an educational psychologist; social care agencies; and anyone else you reasonably request.

There is limited space on the parental views booklet, but if you feel you need to give more information, you can continue onto separate pages and attach them to the document (make sure that your child’s name and date of birth is shown on the additional sheets). It is important to be as thorough as you can, because the local authority needs a full picture in order to make a good decision.

If you have additional reports about your child, you can attach them as part of your parental advice and information. If the reports are up-to-date, the LA should use these and not ask for new ones.

‘The physio at the special clinic that she goes to and the playgroup did a report as well. Basically, I asked, “Would it be possible to do an assessment report and have it ready, so as soon as the LA officially asks, you can send it straight away?”’

If the local authority decides an EHC Plan is not needed they must write to you by week 16 explaining their decision and your right of appeal. They should also provide written feedback about the information gathered during the assessment, including all the reports, as these can be useful for you and the school. There will also be a meeting held to which you will be invited.

If the LA decides an EHC Plan is required, they must send you a draft of the plan, together with copies of all the reports they have received. There is no fixed time limit for this, but it should be by week 16 to ensure the final plan is complete by week 20. Local authorities can choose the format for their EHC Plan but the law details the sections that every plan must include.
When the draft is issued you will notice that the section regarding placement does not name a school, as you have the right to request a particular school or type of school. The local authority must tell you where to find information about the schools and colleges that are available for your child to attend.

You have at least 15 days to decide if you’re happy with the draft plan. It is very important that you make use of this time to check it thoroughly. Does it describe your child accurately? Is all the support suggested in the reports in the provision section? Is it specific enough that any school could read it and know what your child needs? Are you happy to agree the Personal Budget (see below for details) in the plan if you asked for one?

At this stage, you are entitled to request a meeting with your planning co-ordinator to discuss the draft plan. However, parents usually only ask for a meeting if they have serious concerns with the EHC Plan. If you only want to make minor changes you should be able to sort these out over the phone or by email.

Although the local authority usually asks for plans to be finalised within 15 days, if you feel that you need more time to think about the wording and take advice from your Independent Supporter, or organisations such as SEND IAS or IPSEA, it is best to email your co-ordinator to say that you need more time. Some parents may worry about doing this, however, it is important to ensure that you are happy with the EHC Plan and its contents, so you should not feel under pressure to finalise before you’ve had chance to seek advice.

By week 20, the LA should issue the final plan. This will name a school, and the amount and arrangements for a Personal Budget if you requested one.

If you disagree with the final plan you have a right of appeal about some sections: the special educational needs; special educational provision; and the school placement.
Person-centred planning

A key aspect of EHC planning is that the child or young person and their family should be at the centre of the process and the local authority should have regard to their wishes. This is called ‘person-centred planning’ and it ensures that your child’s education gives them the best possible outcomes to prepare them for adulthood. You have the right to be with your child at all interviews, medical tests or any other appointment. If a professional wants to observe your child in the classroom, or talk to them on their own, they should tell you that they are doing this.

What are outcomes?

An EHC Plan will develop a set of outcomes for your child to work towards. Outcomes should be ‘SMART’ – this means they should be ‘Specific, Measurable, Achievable, Realistic and Time-bound).

The Plan is broken down into different sections. It identifies a child’s aspirations (what they want), their needs, the provision they need to meet the needs and the outcomes that the provision will help them work towards and hopefully achieve. Some outcomes will be short-term. Others may be longer term, and could be broken down into smaller steps so that your child can make steady progress. For example:

- Thomas wants to have friends (an aspiration)
- Thomas has social communication difficulties (a need)
- Thomas will take part in a thirty-minute weekly social skills group (provision)
- By the end of the school year Thomas will play with two friends at break or lunch time at least twice a week (short-term outcome)
- By the end of Key Stage 3, Thomas will be able to make and maintain appropriate friendships (long-term outcome).

These outcomes are specific. They are measurable, as staff will be able to document if the interactions are happening. They are achievable and realistic, as they have been broken down into steps to help Thomas to work
towards the long-term outcome. They are time-bound, as we know when they should be achieved.

**Personal Budgets**

You have the right to ask for a Personal Budget as part of the EHC Plan. A Personal Budget is an amount of money identified by the local authority to deliver parts of the provision set out in your child’s EHC Plan. It gives you the flexibility to choose which services and support to use in order to meet your child’s outcomes.

You can find out more about Personal Budgets on page 59. If you have an Independent Supporter they can also help you to find out more about them so you can decide if this might be something you want to consider for your child.

**Requesting a particular school**

You have the right to request a particular school or college if it is:

- a maintained mainstream or special school or nursery school. This includes academies and free schools.
- a Further Education or Sixth Form College.
- a non-maintained special school – these are usually run by charities.
- certain independent special schools approved by the Secretary of State under section 41.

The LA has to agree with this unless:

- It would be unsuitable for your child’s age, ability or special educational needs.
- Your child’s attendance there would be incompatible with the efficient education of others, or the efficient use of resources – meaning it costs significantly more than an alternative school that the local authority thinks is suitable for your child.

**Tips for coping with the EHC Needs Assessment process:**

‘*My memory is terrible, especially for names and I spoke to so many people during the assessment. I was worried I’d forget who was who, so I jotted notes down on a pad: date, time, name and bullet points of what was said. It made me feel more in control.*’
• Have a positive attitude!
• Be polite but persistent.
• Involve yourself as much as possible with the professionals dealing with your case. Don’t be afraid of them, they are normal people and not to be avoided.
• Make a note of the name and contact information of the professionals dealing with the EHC Plan or writing reports on your child.
• Make sure you are sent a copy of each advice or report. Keep a file just for these.
• When dealing with the local authority or professionals involved in writing reports it is advisable to speak to them via email, so that you have a ‘paper trail’ of what was said and by whom.
• If you do anything by phone, always take the person’s name, note the date of the call and what was discussed. If you are told something significant, ask for confirmation in writing, or send a brief email to them noting what was said or agreed.
• Get as much help and advice as possible. Don’t be afraid to ask other parents who’ve been through the assessment process for tips. You can also contact the organisations listed at the end of this chapter.
• Don’t forget it’s your child; you know your child better than anyone. You need to hear what professionals say and consider all the options, but be ready to stick to your guns if need be!

Annual Reviews

Your child’s EHC Plan must be reviewed by the local authority every 12 months as a minimum. You should get at least two weeks’ notice of the meeting and you can take someone along with you if you wish. Your child should also be actively involved in a way that best suits them.

Annual Reviews are usually held at the school. The other people who must be invited are the school, the local authority planning coordinator and a representative from both health and social care. Other people involved in working with your child, including private practitioners, can be asked too.

Not everyone attends the annual review but everyone who is relevant (including you as parent)
should be asked for their advice and information about the child beforehand. This should be sent to you two weeks before the meeting. It’s important that you have the chance to read these reports before the review so that you can think about what you would like to get from the meeting. If you don’t get them in enough time you can ask to postpone the review.

The school will usually arrange the annual review meeting and report to the local authority after so they can complete the annual review process. The meeting must focus on your child’s progress in meeting the outcomes in their EHC Plan. In particular, are any changes needed in the support they get to help them achieve their outcomes? Have the child’s needs changed? Do the outcomes need updating? Within two weeks of the meeting the school must send a report to the local authority. You should get a copy. Check it over to make sure it matches what was said or agreed at the review. Within four weeks, the local authority must decide on one of three things:

• To continue with the existing EHC Plan.
• To amend or change the EHC Plan.
• To withdraw or ‘cease to maintain’ the EHC Plan.

If the local authority decides to change the EHC Plan, there is a process with time limits that allow for you to comment and appeal their decision if you don’t agree. It is important to understand that an EHC Plan can only be changed through the annual review process. If the LA decides to withdraw the EHC Plan you can appeal if you disagree. You can also appeal if the LA decides not to amend the plan after the annual review and you think it should be changed.

Changing schools

If you want your child to change school, other than the usual move from primary to secondary school, you will have to ask the local authority to change the name of the school in your child’s EHC Plan/Statement.

You have the right to ask for another West Sussex state school
– mainstream or special – as long as the school you are requesting is like-for-like, and it’s at least 12 months since you last made a request or since your child’s EHC Plan/Statement was issued or last amended.

The local authority has eight weeks to consider your request and you can appeal if you are unhappy with their decision. You don’t have the right to ask for a move to an independent special school, but if you feel this is what your child needs, you can request that the local authority reassess your child.

If you move out of West Sussex, the new local authority must honour your child’s EHC Plan (or Statement if this still applies), and place them in an appropriate school while they are deciding whether to review your existing EHC Plan/Statement or undertake a new assessment. If your child is at an independent placement funded by the local authority, the new local authority must continue to pay the fees until they change the EHC Plan.

‘When we wanted to get him out of the SLD school into an MLD, it was a terrific struggle, but we had a very good EP, she was absolutely outstanding, and the speech therapist was very helpful, too. We really pushed and pushed, and we were lucky, we did get him into the MLD school.’

Transfer between phases of education

When your child is due to move from one phase of education to the next, such as from pre-school to primary school, or primary to secondary school, there are special rules. The annual review must happen early enough to allow time to plan for the move. The EHC Plan must be amended by the 15th February of the year the child is due to transfer to a new setting. If they are moving into Further Education, the deadline is 31st March.

The amended EHC Plan must name the new school or college. The aim is to allow everyone time to plan for a smooth transfer. For a child coming to the end of primary school, the annual review in Year 5 should detail what they will need at secondary school.
so you have time to look at the options. A review early in Year 6 should pull this together for the local authority to complete the amended EHC Plan by 15th February. This leaves plenty of time for liaison between the primary and secondary school, visits, organising staffing or equipment and so on. It also allows time for an appeal if you are unhappy, and for this to be resolved before September.

Preparing for adulthood in annual reviews

From Year 9 onwards, each annual review should focus on preparing for adulthood and look ahead at what will help the young person move towards things like employment and independent living. This is covered in more detail in our title, Making Sense of Adult Life, which is free to parent carers, see page 80 for details.

Review or re-assessment?

If you feel your child’s EHC Plan needs changing you can usually address this at annual review. However, there may be circumstances when parents think their child requires a whole new EHC Needs Assessment, for example, if they and the local authority are not seeing the child’s needs in the same way, or if the child’s needs have changed significantly. If you or the school request re-assessment the local authority has 15 days to say whether they agree. If they refuse you have the right to appeal. If they do go ahead, the process and timescales are the same as for initial assessments.

Appealing to the SEND Tribunal

We have mentioned a few points at which parents have a right of appeal to the Special Educational Needs and Disability First Tier Tribunal (SENDIST).

If you don’t agree with the local authority it is usually worth having at least one more try at resolving things locally. You can always ask for a meeting with your Planning Co-ordinator and the SENAT manager. You can also ask SEND IAS for support with this, see page 113 for details.

Before you can lodge an appeal to the tribunal you have to prove
that you have discussed the possibility of mediation with a mediation adviser. Should you choose to go ahead to tribunal without using mediation, you must send in a ‘mediation certificate’ with the appeal paperwork to show that this option has been considered.

For some issues you will not have to consider mediation – for example it does not apply if you only wish to appeal the school placement named in section I of the EHC Plan. With this, you can go straight to SENDIST.

Parts of an EHC Plan relating to your child’s health and social care needs cannot be considered at tribunal, but if you are unhappy with the content, you can still use disagreement resolution and/or mediation and then use the relevant complaints procedures if necessary.

**SENDIST appeals**

SENDIST is an independent body that hears parents’ appeals against local authority decisions on EHC Needs Assessment and EHC Plans. It also deals with some claims of unlawful disability discrimination in education.

There are strict timetables for making an appeal and these differ for SEN appeals and disability discrimination claims. It’s important to get advice as early as possible if you are considering appealing.

You can appeal to the SEN First Tier Tribunal (SENDIST) if:

- The LA refuses to assess your child after you or the school have requested this.
- The LA decides an EHC Plan is not needed after assessing your child.
- You disagree with the EHC Plan sections that describe your child’s special educational needs, the special educational provision specified, the school, or type of school named.
- You disagree with an amendment to any of these sections.
- The LA refuse to reassess your child.
- The LA decide not to amend the EHC Plan after review or reassessment.
• The LA decides to stop maintaining the EHC Plan.

In these cases, the tribunal can direct the local authority to change their decision.

Going to tribunal is a stressful experience and not to be undertaken lightly. It is the last resort for parents who have been unable to resolve matters with the local authority in any other way. Parents who decide to go to appeal need to have energy and endurance, be well prepared and have access to the best possible advice and support.

While the tribunal encourages parents to represent themselves and will take care to treat you fairly, many have found it a daunting experience. If you cannot find someone able to help you prepare your appeal, you can ask SEND IAS for support as all their advisers have legal training.

‘Our SEND IAS adviser was extremely knowledgeable with regard to the information we had to include in our appeal... without her we would have been completely lost.’

Alternatively, you may think about instructing a solicitor but this can be costly. If you take this route make sure they specialise in education law. You may qualify for free legal assistance, so be sure to ask about this and the fees, before going ahead.

‘It was an awful hassle to go to appeal, but it was important that the integrated activities he was having should continue. We just had the energy to do it, I suppose.’

If you feel your child has been discriminated against on the grounds of their disability, you should start by complaining to the head teacher and governing body of the school. If this does not resolve the matter, you can make a claim of unlawful discrimination against a school on behalf of your child to the SEN First Tier Tribunal (SENDIST). Some claims of unlawful discrimination will go to admissions appeal panels or, for exclusions, to independent appeals panels.
Children who still have a Statement of SEN

Although many children and young people with Statements of Special Educational Needs (SEN) have been transferred to EHC Plans, at the time of going to press the transfer process is still ongoing and by April 2018, all Statements should have been switched to EHC Plans.

If your child still has a Statement this remains in force. All the details in their Statement and the rights attached to it carry on unchanged until their Statement ends – either because they transfer to an EHC Plan or they finish their education. In this section we look at how things work whilst your child still has a Statement and the process for transferring a Statement to an EHC Plan.

Rights while you have a Statement of SEN

The local authority continues to be responsible for making sure the provision set out in your child’s Statement is delivered. The Statement must still be reviewed annually. The process for reviewing Statements and EHC Plans is very similar, so schools will approach them in much the same way.

Nothing changes in terms of who is invited to give their views or attend the annual review. You should still get the papers two weeks beforehand. The meeting should look at your child’s progress over the year and go over the Statement. If your child is in Year 9 or 10 the meeting should include looking ahead at the transition from school to college and beyond that to preparing for adulthood.

After the annual review meeting a report must go to the local authority and, as a result of any recommendations that are made at the meeting, the LA will decide on one of three things:

- To continue with the existing Statement.
- To amend or change the Statement.
- To withdraw or ‘cease to maintain’ the Statement.

If the local authority decides to change the Statement, they will
give you a proposed amended version and follow the same procedures and timescales used when producing a new Statement, which means you have the chance to put your views and appeal the decision if you can’t agree. If major changes are needed, you and the local authority could agree to transfer to an EHC Plan instead. If the local authority decides to withdraw the Statement you can appeal if you disagree. Parents can also appeal if the local authority decides not to amend the Statement after the annual review and you think it should be amended. Again, SEND IAS can help you with this, see page 113 for details.

Transferring from a Statement of SEN to an EHC Plan

The legal test for whether you need an EHC Plan is the same as it was for a Statement. This means that most children with a Statement will need to be transferred to an EHC Plan. The exception will be children whose Statements cease. This can be because they have made so much progress they no longer need a Statement or an EHC Plan. This is unusual, but it does happen. You can appeal if you disagree.

The process of transfer should begin with a transition review, a bit like an annual review but it will trigger the start of the EHC Needs Assessment, which was explained earlier in this chapter.

For many children, the assessment should be more straightforward because there will already be plenty of advice and information about the child from the Statement. But if the reports on your child are quite out of date new ones should be requested. You will also want to be sure that nothing that’s still relevant in the Statement fails to find its way into the EHC Plan, so you need to tackle the transfer with the same care and attention as when your child or young person was first issued with a Statement.

However, bear in mind that a Statement and an EHCP are very different things, so it’s also important to ensure the outcomes are not simply objectives lifted from the Statement.
Amaze Independent Supporters can help parents and young people with the EHC transfer process. For contact details, see page 90.

**How to choose a setting for your child**

When considering an education setting for your child, you will be looking for a placement where they will be able to learn and develop in confidence and independence.

**Choosing a pre-school setting**

If your child’s SEND has been identified early, then this will be a key factor in deciding what type of setting will best suit their individual needs. However, with the right support in place, most children with SEND are able to go to local playgroups, pre-schools, nurseries and nursery classes in mainstream schools.

All playgroups and nurseries should welcome children with SEND but their experience and facilities vary. You can find out more about childcare settings through the Family Information Service at: www.westsussex.gov.uk/fis.

All childcare settings, including holiday playschemes and breakfast clubs should have a special needs policy and a Local Offer document, as well as a member of staff who is the Special Educational Needs Coordinator (SENCO). Ask about this when choosing a place for your child.

**Specialist pre-schools**

If your child would struggle in an ordinary pre-school, you may find that a more specialist Early Years setting would suit their needs.

Chailey Heritage School, near Lewes, works with children from the age of three who have complex physical disabilities, communication difficulties and high health needs. However, in order for a child to be considered for a place at the school, the local authority (LA) has to request it, so seek advice as early as possible.

Ingfield Manor School in Billingshurst has a pre-school (the Pre-school and Assessment Service) for children with neurological motor impairments, such as cerebral palsy, and associated learning problems.
The pre-school provides conductive education incorporating the early years’ curriculum. The local authority would have to agree to support and fund a place.

**Preparing your child for the move from pre-school to school**

Children who have additional needs may need more support than their peers to help their transition from pre-school to school. It is helpful if the family and professionals involved with the child have a meeting beforehand to discuss and plan for the needs of the child to ensure their transition goes as smoothly as possible. To find out more, go to www.westsussex.gov.uk and search for ‘including all children’, then click on ‘supported transition’. You can also find general information for all parents about preparing your child for school on the council’s website by searching for ‘moving from pre-school to primary school’.

**Choosing a school**

- **Mainstream schools**: most children are educated in mainstream school, and this includes most children with EHC Plans. As a parent, you have the right to ask for your child to be included in a mainstream school even if they have the kind of needs often catered for by special schools.
- **Special schools**: there are 12 special schools in West Sussex, catering for a range of special educational needs and disabilities. There are schools for children with complex needs, mild to severe learning difficulties and social, emotional and behavioural difficulties. Most children at special schools attend full-time, but some may have a dual placement with a mainstream school.
- **Specialist units**: 26 mainstream schools in West Sussex have specialist units that cater for children with specific needs such as autism, speech and language difficulties, hearing impairment, specific learning difficulties or dyslexia. Children spend some of their time in mainstream classes and some in the unit or facility.
- **Independent placements**: sometimes, it may be that a child’s needs cannot be met in a school run by the local authority and it may be necessary for them to be
placed in an independent specialist school. These may be out of county, and/or residential. Some independent specialist schools are only available to children from Key Stage 2 (usually aged 7). Independent placements are costly, and are only considered if a child’s needs cannot be met elsewhere in the county. You can find a list of independent special schools at: www.gov.uk/government/publications/independent-special-schools-and-colleges.

How can I tell if a school is right for my child?

‘How can you tell if the school is right? You just have to go and see, don’t you, and you know what your child is like. Can you picture them being there? It’s just the same as ordinary children.’

Parents say that it can feel like there is very little choice if your child has SEND, particularly if their needs can only be met in a special school or unit. Whatever the school, perhaps the key question to ask is: ‘can this school meet my child’s additional needs?’ With mainstream schools this can be hard to assess.

All mainstream schools are expected to be inclusive but, inevitably, some have more experience or enthusiasm than others. Schools are covered by the Equalities Act 2010 – there is more on this later in the chapter – but it is useful to know that the duty not to discriminate also applies to prospective pupils and the admissions process. When you visit a mainstream school:

• Talk to the head and try to get an idea of the school’s attitude towards children with SEND, and more specifically to your child’s specific needs. Have they had a child with similar needs before? Look at the school’s SEN Information Report and their Local Offer.
• Meet the school’s Special Needs Co-ordinator (SENCO). Find out how much time they have away from teaching to devote to this role.
• You may wish to find out how many children with SEND are on the roll. If a school has a significant number of children, they are more likely to be experienced. However, if the SENCO’s role is part-time, will he or she be spread too thinly if there are many students?
• Try to find out what resources the school has for children with special needs, such as extra classroom helpers, learning support assistants and visiting specialists. The local authority gives schools extra money to support children with SEN, so ask the school about the extra support they offer.

‘Nursery was such a struggle, so we knew a mainstream classroom wouldn’t work for our son. When we walked into the unit, it was a gut feeling, but we knew we’d found the right place.’

What should you expect from the school?

Your child’s school MUST:

• Provide the name of the teacher responsible for children with special educational needs, usually called the Special Educational Needs Co-ordinator (SENCO).
• Explain the way it decides which children need help and how it will be given, in line with the SEND Code of Practice.
• Describe how it will work closely with parents
• Publish a SEN Information Report annually to parents on its implementation.
• Publish a Disability Equality Scheme and information about access to the school for disabled children and a plan for how it will improve this access over time.
• Make reasonable adjustments to avoid putting disabled children at a disadvantage.

SEND law

When your child has SEND and requires additional support with their education, it can feel very daunting when people start throwing around terms such as ‘Code of Practice’ and the ‘Children’s and Families Act’.

Showing that you know what the law says and what your child is entitled to can be incredibly effective in meetings, but it can be a real struggle to make time to read these huge documents, not to mention understanding all the legal jargon and how it relates to your child and their situation.

We will give you a brief overview of how SEND law fits together and links to the legislation so you can read up on it if you choose
to. If this seems too daunting, the good news is that there are several organisations that have lots of useful resources, explaining the law more simply. Many also have advice on tackling common problems, so you may be able to sort out issues that arise yourself and without the need to pass a law degree!

**The Children and Families Act, 2014**

In September 2014, the new Children and Families Act 2014 came into effect in England. This is ‘statute law’ or a legal framework that is passed by Parliament. The legal rights of children and young people with SEND are set out in Part 3 of the Children and Families Act. To read it, go to: www.legislation.gov.uk/ukpga/2014/6/part/3/enacted.

‘A Local Authority must have regard to... the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.’ Children’s and Families Act, Part 3, 19 (d).

**SEND Code of Practice, 2015**

You may have also heard people refer to the ‘Code’ or ‘Code of Practice’. This is the *Special Educational Needs and Disability Code of Practice 2015*, which is the statutory guidance on duties, policies and procedures relating to the Children’s and Families Act.

It sounds complicated, but to put it simply, the code is what organisations such as local authorities, schools, early years providers, NHS trusts and clinical commissioning groups must comply with (unless there are exceptional reasons not to). The Code is divided up into chapters, covering areas such as Early Years education, schools, preparing for adulthood and Education Health Care Plans (EHC Plans). So although it seems long, you don’t have to sit down and read it all. You can look at the parts that are relevant to your situation. It is especially useful for the EHC process, as it explains all the steps and the timeline that must be followed. To look at the Code go to: www.gov.uk/government/publications/send-code-of-practice-0-to-25.
‘[Local authorities and other organisations] must have regard to the Code of Practice. This means that whenever they are taking decisions they must give consideration to what the Code says. They cannot ignore it. They must fulfil their statutory duties towards children and young people with SEN or disabilities in the light of the guidance set out in it.’ SEND Code of Practice 2015, page 12.

Regulations and Case Law

There are two other parts to the legal jigsaw. The first is regulations – for SEND law, these are the Special Educational Needs and Disability Regulations 2014 and the Special Educational Needs (Personal Budgets) Regulations 2014, which contain detailed provisions, including time limits, that organisations must follow. The regulations can be amended and in fact have been several times since they were passed. For more, go to: www.legislation.gov.uk/uksi/2014/1530/pdfs/uksi_20141530_en.pdf and: www.legislation.gov.uk/ukdsi/2014/9780111114056.

The final part of our legal jigsaw is case law. Where the law is ambiguous and a case has been brought to court, the judge’s interpretation of what the law intends can become part of the law for others to follow. This is known as ‘case law’. Often, lawyers bringing a case to court will use relevant examples of case law (or ‘precedent’) to strengthen their argument.

Who can I turn to for advice?

There are many organisations offering parent carers advice on SEND law and education issues. Locally, SEND IAS can offer advice and support to parents and young people. See page 113 for details.

Nationally, IPSEA has a helpline offering a callback service to parents who need advice, as well as resources and model letters to send to local authorities and schools. For more information go to: www.ipsea.org.uk.

The Council for Disabled Children has many useful resources, including a guide to SEND law, an overview of Part 3 of the

Organisations such as Contact a Family (www.cafamily.org.uk), SOS SEN (www.sossen.org.uk) and Special Needs Jungle (www.specialneedsjungle.com) also have a wealth of information on their websites and Contact a Family also can also offer advice to parents.

The Equality Act and schools

Since October 2010, schools have come under the Equality Act 2010, and have a duty not to discriminate against disabled pupils and prospective pupils in the way they provide education and ‘associated services’. It also applies to admissions to school and exclusions. This means that they must not treat your child less favourably than other children for a reason related to their disability. If they do treat a disabled child less favourably, they have to prove this was justified and there was nothing they could have done to avoid it. They also have to take reasonable steps to ensure that disabled children coming to the school will not be put at a substantial disadvantage compared to other children. The definition of ‘disabled’ is not the same as ‘special educational needs’, but can cover conditions we might not think of as a disability, such as dyslexia or emotional and behavioural difficulties, if they cause a substantial adverse effect on the child’s day-to-day activities.

It is worth noting that areas covered by the duty not to discriminate are quite wide. They include: school trips; after-school clubs; play; lunchtime arrangements; and access to the school curriculum.

The Equality Act 2010 gives guidance to schools about what they should do and includes examples of situations where a parent could use this law to protect their child’s interests.

Bullying

Children with SEND are more at risk of bullying. Sometimes, they may be more likely to bully others, too. Bullying is very distressing for children and parents, but there are things you can do to support your child if you think they are being bullied. The first step is to talk to your child and read the school’s anti-bullying policy. Thereafter, you can contact the West Sussex Action Against Bullying Helpline on: 0333 014 2904.

Exclusion

It has been shown that children with SEND are at increased risk of being excluded at some point in their school life. Exclusions can be fixed term for a specific number of days, or permanent. The school must write to tell you that your child has been excluded, why, and for how long. There should also be a reintegration strategy in place before your child returns to school.

Sometimes, it’s only when your child faces exclusion that you realise they have special needs and these are not being met at school. Schools are meant to take all possible steps to avoid the exclusion of children with special educational needs. This could include reassessing their needs, or requesting an EHC Needs Assessment. If your child is excluded, even for a very short period, it is a very worrying time for parent and child. There are options for appeal, but you will need to seek advice and we would suggest that you speak to one of the organisations listed on the facing page.

Some parents of children with special needs also find that schools ask them to collect their child early, or send them home whenever there is a problem. Sometimes, they suggest the child only comes to school part-time. Although the school does not call this a formal exclusion, in practice it is excluding the child. Informal exclusions of this kind may be a sign your child is not getting the support they need and is also illegal.

Again, if necessary, you may wish to speak to some of the organisations listed below for
advice on how to tackle this, but in the first instance you should speak to the school and indicate that your child’s needs are not being met. You should also ask what support they plan to put into place to rectify the situation so your child can access education.

Who can help with education matters?

Because education is complex and often problematic for parents, it’s important you get independent help if you need it, especially if you are in disagreement with your child’s school or the LA. If you are on a low income, you may be able to get free legal advice from a solicitor.

Locally, the West Sussex SEND Information, Advice and Support Service (SEND IAS) offers support, advice and information to parents who have a child with special educational needs. They are described as an ‘arms length’ service, which means although they are funded by West Sussex any advice they give is ‘impartial, confidential and free’.

It provides a range of services including: a confidential helpline; information about SEN processes; and a small team of Independent Parental Supporters (IPS). For more, call: 0330 222 8555 or email: send.ias@westsussex.gov.uk. SEND IAS also have Young Person Advisers who can support young people with SEN and help them express their wishes. They can be emailed on: cyp.sendias@westsussex.gov.uk.

Some of the parent-led special interest groups such as AFASIC: www.afasic.org.uk; the Down’s Syndrome Association: www.downs-syndrome.org.uk; and the British Dyslexia Association: www.bdadyslexia.org.uk have considerable expertise in the field of education and will support and act as advocates on behalf of parents.

Nationally, organisations such as IPSEA: www.ipsea.org.uk; NASEN: www.nasen.org.uk; and Network ’81: www.network81.org.uk are useful sources of support and often, they have informative publications, too.
Campaigning organizations such as the Alliance for Inclusive Education, Centre for Studies on Inclusive Education, and Parents for Inclusion may be helpful for parents who feel strongly about their children being educated within mainstream schools.

The Advisory Centre for Education runs a helpline that you can call for advice on: 0300 0115 142. It also has information and advice on a wide range of education issues at its website: www.ace-ed.org.uk.


Contact information for all of these organisations can be found in the directories at the back of this book.
When you have a child with SEND, daily life is often more challenging. Getting the right support can make all the difference, so this chapter will focus on the type of help that is available to families and how you can access it.

Some services for children with SEND are county-wide. It’s also worth looking at mainstream services, too, as these can also be useful. Mainstream services are provided according to which area of the county you live in, so have a look to see what is available locally.

When considering what support you need, think about what will best benefit your family – every household is unique, so your needs will be different to those of other families, even if you have children with the same additional needs or disability.

If you know other parents who have children with SEND, pick their brains! Ask them where and how they got equipment, access to a service, or simply how they cope. Don’t be afraid to ask professionals what is available. Local and national organisations can also be a great source of information and support. Consider asking friends, relatives or neighbours for support, too, as many will be happy to help.

How to access services

Your health visitor

When your child is very young, your health visitor is a useful first point of contact. They should be regularly monitoring your child’s development and listening to any concerns you may have, and will usually refer your child to a specialist if they think it necessary, or if you ask them to.
Most health visitors will work with children up to the age of five, but there are also specialist health visitors for children with SEND, who work with children aged up to eight and beyond in some cases.

**Early Years Hubs**

There are 44 Children and Family Centres across West Sussex, all of them offering support and services to families.

For those who have children with SEND, there are also eight Early Years Hubs, which are located in Children and Family Centres (CFC) around the county. The hubs offer additional services, advice and activities specifically for children with SEND.

Each hub runs ‘Play and Learn Plus’ sessions and some offer the chance for your child to access sensory areas and sensory toys. Sessions are also an opportunity for you to meet other parent carers. All hubs are wheelchair accessible and some also have hearing loops.

The hubs are based at: Bognor Nursery School and CFC; Boundstone Nursery School and CFC (Lancing); Chichester Nursery School and CFC; Durrington CFC; East Preston CFC; Horsham Nursery School and CFC; Langley Green CFC (Crawley); and Sidney West CFC (Burgess Hill). For contact information, see Essential contacts page 155.

**Recent changes to services**

In April 2017 there were changes to the way in which services were organised. Many support services have been brought together under the umbrella of ‘Integrated Prevention and Earliest Help’ (IPEH) within WSCC, so some teams have been reorganised. Services marked with an asterisk (*) now come under IPEH.

For parent carers, the way in which the majority of services are accessed has not changed. You can ask for support through many channels, including your health visitor, local Children and Family Centre, the Early Childhood Service, Family Support or West Sussex Young Carers, for example.
What has changed is that whereas teams used to focus just on the child or young person now, no matter which team you approach, the support worker who is assigned to your family will assess the family’s needs as a whole. This ensures that everyone in the family gets the support they need, not just the child with SEND, but also parents and any siblings in the family.

What is Early Support*?

Early Support focuses on giving each child the best start in life, by helping parents-to-be and families with young children. The aim is to work holistically with families as soon as possible, as the more fully families are supported in the early years, the less likely they will need higher levels of help later on. However, if families need additional support beyond what they are already receiving, workers can identify this so that a higher level of support can be put in place without delay.

Some families may only need support temporarily, but the thought of ‘going alone’ after you’ve had help can seem quite daunting. So rather than stopping abruptly, help will be gradually stepped down, so that support workers can be sure that families are confident and able to fully manage on their own.

Types of Early Support

There are a number of ways in which early help is given to parents. These interventions and support are provided to families where:

- their needs are not being met by routine or ‘universal’ services
- they do not meet thresholds for statutory interventions.

Family Support*

This is a West Sussex service providing personalised support, including home visiting, for families with children and young people aged up to 19 (25 for young people with SEND). Support workers will help parents by discussing strategies and solutions to everyday family issues and introduce you to local family activities.
If you are concerned about your child’s development, you can raise your concerns and get advice and support for your child. If it is determined that they need extra support an Early Help Plan will be drawn up for them. To find out more, speak to your local Children and Family Centre (see Local Directory for details) or speak to your health visitor, GP, midwife or preschool.

Specialist Key Workers*

Some families whose children have multiple complex needs require coordinated multi-agency support to prevent the need for statutory social care intervention. Families may receive help from the Think Family Key Worker* Service or other Specialist Key Workers.

Multi-Agency Safeguarding Hub (MASH)

The MASH aims to provide a single and consistent point of access to advice, guidance and decision making about the right level of help needed to keep each child safe or achieve change as part of an early help response.

Families can contact the MASH to access early help, but they may be referred to one of the other services mentioned previously if they are more appropriate. For MASH contact details, see the Local Directory.

Getting help from a social worker

Some of us didn’t ask for help until we reached crisis point and felt we couldn’t manage any more. Other parents realised, as they gradually got to know the SEND system, that the backing of social workers was essential for getting the help they needed.

Before you meet the social worker, try to think about how your life has changed and become more difficult as a result of caring for your child with special needs, and what kind of help you think you all need, now and in the future.

‘I think you cope, you don’t really ask for help when you’re feeling articulate. You usually end up waiting until you’re not articulate and everything’s gone to pot, and that’s when you need these people.’
Many of us only asked for help when we were desperate and felt we couldn’t cope any more. If you think that you need help, try to ask for it before you reach crisis point.

‘What I realised after I’d asked for help was that my entire life had been out of control for ages. I thought I was coping – I thought I was keeping the lid on the pan.’

**To get help from a social worker**

If your child has severe or complex disabilities then you can be assessed for support by the Child Disability Service (CDS). A member of the team will undertake a Needs Assessment and, if they decide you and your child are eligible for support, they can provide help with short breaks, care in the home and activities for your child.

Any parent can request an assessment for a child under 18 years of age. You can contact them by phone on: 01403 229888 or by email at: cdt@westsussex.gcsx.gov.uk.

You will speak to a qualified social worker who will take full details for your child. They can provide advice and information, and direct you to an appropriate team or organisation if you do not meet their eligibility criteria. If an assessment is needed, the referral will be passed on, either to the Referral and Assessment Team, or if your child meets their criteria it will be passed directly to one of the three child disability teams.

The teams have a duty to carry out an initial assessment within ten working days and, if necessary, a more in-depth core assessment within 35 working days.

**What happens when the social worker visits?**

The social worker will see your child according to the plan agreed with you, taking into account any disability or particular needs. They will carry out interviews with your family. Assessments will take account of your needs as a carer, and those of siblings or young carers, as well as those of your child.
If your child needs equipment or adaptations, an occupational therapist from the county council will carry out their own specialist assessment, see page 128.

There are regulations that require social services to make formal plans for supporting children. This includes producing a Child In Need Plan, which is agreed with the parents and involved agencies. The plan set outs which agencies will provide which services and includes any expectations of you and your family. The plan should then be regularly reviewed. The Child In Need Plan can be updated if the needs of your child and family change over time. If you feel that things aren’t going well, you should discuss this with your social worker.

Tips for working with social workers

Many of us have had lots of contact with social workers over a number of years and we suggest you have a look at chapter three for some practical tips for working with professionals. Here are a few extra tips:

• Just because you get a ‘no’ this time, don’t take that as a final answer. And even if you get a ‘no’ now, don’t be afraid to ask again as your needs and your child’s needs change.
• Find out what other parents have and how they managed to get it. Inside knowledge can be very useful!
• Get people such as your GP, consultant and health visitor on side. Ask them to write letters for you to explain what you need and why it is so important.
• It’s vital to build up a good relationship with your GP and social worker so that when you are desperate they already know who you are and what you and your child’s problems are.
• However, if you’re not happy about the way things are going in your contact with social workers, don’t feel you can’t say so.
• Challenging decisions or making complaints can be stressful, but unfortunately it is sometimes necessary.
Who’s who?

**Community Family Worker:** works in the home alongside the parents, offering practical and emotional support.

**Duty Officer:** a social worker or social work resource officer who is taking their turn on the ‘duty desk’, taking new referrals and dealing with emergencies.

**Family Support Worker:** provide a personalised support including home visiting to families. Can also signpost families to other teams and organisations for further support.

**Key Worker:** keeps families informed about services for their child and ensure professionals have all the information they need to provide a good service. The key worker coordinates service provision to minimise duplication and stress for the family.

**Occupational Therapist (OT):** Social care employ their own team of occupational therapists, within the Independent Living Service. The team offers assessments, advice, equipment prescription and housing adaptation advice for individuals with long-term disabilities within their home or foster placement.

The NHS Occupational Therapy service carries out interventions: within schools; assessment and advice for hospital discharge and short-term needs of under six months. It also has input within Child Development Centres, Children and Family Centres and nurseries. Health occupational therapists can also provide some equipment for the home.

**Social Workers:** can offer advice and counselling to families. They assess what kind of help you might need and try to get it for you. They can offer ongoing emotional and practical support to families.

**Think Family Key worker Service:** helps families with multiple or complex needs who require coordinated multi-agency support, to prevent the need for statutory social care intervention.
Phrases you may hear

**Care Package:** this is the extra help you get after your needs assessment. It might, for example, include short breaks, a session with a community family worker or some social work support.

**Carer’s Assessment:** if you are the person most closely involved in looking after your child and he or she is having, or is eligible for, an assessment of their needs, you will be entitled to a Carer’s Needs Assessment in your own right. Ask for one to be done.

**Multi-disciplinary/multi-agency:** where all the professionals or organisations providing treatment or support come together to assess or discuss your child or family situation.

**Needs Assessment:** to decide on the extra support your child needs, the social worker will come to your home to find out more about your situation. They then write a report, giving details of your needs. This report is called an Initial Needs Assessment. Any help your child receives should be based on it. It also includes the needs of parents/ carers and the family as a whole, including siblings.

**Outreach:** this is where a worker comes out to you and/or your child, rather than you having to go to them.

**Who pays?**

Most help available for families is free. You shouldn’t be charged if you are on Income Support, or receiving Working Tax Credit or Child Tax Credit (above the family element). Budgets are almost always very stretched. Many parents are happy with the way their needs have been assessed, but then find there’s a waiting list for those things their assessment says they need, like outreach and short breaks.

If your child has been assessed as being eligible for social care, they may be allocated a Personal Budget, which is the amount of money the local authority has decided is necessary to arrange your child’s care and
support. A Personal Budget can be allocated to you directly as a Direct Payment so that you can organise and pay for things like short breaks yourself. If you prefer, the local authority can hold onto the money and arrange support on your child’s behalf. Or you can have a mixture of both. So if you’ve been assessed as needing a service, ask your social worker or short breaks assessor to explain more about Direct Payments and Personal Budgets and how they could work for you.

If your child’s disability involves on-going medical treatment or help, the local health authority may be asked to contribute towards the cost of extra help such as outreach care. This is known as ‘joint funding’. However, it can take a long time to get everyone involved to agree on who will pay for what.

**Short breaks or respite**

Short breaks are organised activities or care (outside of school) that gives your child a chance to have fun and socialise, and you a chance to take a break from your caring responsibilities.

A short break might be an inclusive after-school or holiday club, a social group for children with similar disabilities, holiday playschemes or a few hours care in your own home. It may also be an overnight or residential stay if your child has more complex needs.

‘When I felt guilty about having some ‘me time’ a friend soon set me straight, saying, “You can’t pour from an empty cup, Helen. You need to look after yourself to be able to look after your family!” and I realised she was right. I can’t give my all if I am completely drained.’

The other benefit of a short break that works is that it can be a great confidence booster, for both you and your child. You find out that you can let your child go, and your child finds out they can enjoy life away from the family. Some of us have found that this really pays off in the long-term, because our children have learned to adapt to new situations and experiences much better than they might have done otherwise.
Don’t be put off, however, if the first short break you try isn’t a good fit. Sometimes you need to try several before you find the right one for your child. It is well worth the effort to get it right, though. Many of us have found that short breaks are an absolute life saver and also something that our children really look forward to attending.

Your local authority has a duty to tell you about their range of short breaks available, their eligibility criteria and how to apply. You can find out what is available in your area by looking at the Local Directory at the back of the book, where Short breaks entries are marked ‘SB’. You can also look up short breaks providers on the Local Offer, see page 8 for further details.

**Who can access Short Breaks?**

West Sussex County Council Short Breaks Services are available for disabled children and young people who are resident in the county. Daytime short breaks can be accessed by any child under 18 years with additional needs in receipt of middle or higher rate Disability Living Allowance (or the standard or enhanced rate of Personal Independence Payments (PIP) if over 16). For families of children and young people who have a similar level of need but are not receiving DLA, short break providers offer a simple self-assessment to assess eligibility.

You can organise daytime short breaks and short-term individual one-to-one support yourself directly by contacting the short break provider. You should not expect to pay more for your child to attend than any other child.

If you want your child to access overnight short breaks, you will need to contact your local children’s social care team for an assessment of need. If your child meets the assessment criteria and is considered eligible for overnight short breaks, social care workers will work with you to draw up a care plan that sets out the kinds of support they will get. This plan (which may be part of their EHC Plan, if they have one) will be reviewed regularly.
Bear in mind that more specialist short breaks can be hard to get. There is always a heavy demand. You will have to jump hurdles and will probably have to wait. But it’s well worth the effort. Good respite care can make a huge difference to your ability to cope.

Care at home and in the community

There are a number of organisations in West Sussex that provide care at home and in the community, including:

Crossroads Care

‘I had two people from Crossroads who came and stayed in the house and played with her. The women who came in loved children, and they were brilliant. They were all mums and they brought an enjoyment the house when I couldn’t, when I was struggling.’

Crossroads Care is a charity that provides regular respite care in your own home to give you a break as a carer.

The scheme’s assessor visits to assess your needs, then you make an agreement about what would help most. Crossroads Care workers can come and play with your child for a few hours a week or month, or help out during holidays, when perhaps you want to spend some time with your other children. Visits are at the times you need them most, such as after-school, evenings, or weekends, depending on staff availability. Up to four hours a week is available per family for twelve weeks. For further information, contact Crossroads Care on: 01903 790270, or email them at: admin@crossroadscare-sc.org.

Fun and Breaks (FAB)

This county council service matches families with disabled children with volunteer carers who typically give two hours per week to families, enabling them to take a break. Volunteers can help children to access activities such as swimming, Brownies, bowling, sport activities, or provide a short break within the child’s own home.
To access Fun and Breaks, your child should be in receipt of medium or high care component of Disability Living Allowance, or have a comparable need, and should not be receiving other significant Short Breaks support, such as a Personal Budget, for example.

You can contact Fun and Breaks directly on: 01243 777100 or email: fab@westsussex.gov.uk.

Children’s Continuing Care Service

The NHS provides health care in a non-hospital environment to both children and adults who have substantial or critical needs arising from a disability, illness or injury. To qualify the person in question must have a primary health need and have a complex medical condition with substantial ongoing care needs.

Continuing Care is provided after an initial assessment by a relevant health or social care professional. This is followed by a more detailed assessment by a team of professionals which is co-ordinated by a Continuing Care Nurse. To find out more ask a health professional working with you and your child for more details.

After-school, holiday clubs and buddying schemes

For many parents, the most helpful kind of short break is an activity or playscheme that takes place after-school, at weekends or during the school holidays. More information on these sorts of options are listed in the next chapter and can also be obtained from the Short Breaks Team by calling: 0330 222 2562, or email: short.break.team@westsussex.gov.uk

Childcare

The Family Information Service has a list of registered childminders, playgroups, nurseries and after-school clubs in West Sussex. It offers an extra support service that can help you find suitable childcare if this might not be straightforward for your child. For more information, call: 01243 777807 or email: family.info.service@westsussex.gov.uk.
**Foster care**

West Sussex County Council sometimes use their fostering service to provide overnight or short breaks for children and young people with special needs. The children and young people are cared for in the foster family’s own home. All carers go through a rigorous fostering assessment and care is taken to match suitable families.

**Residential services**

There are a number of facilities in West Sussex providing short and long-term respite care for children with special needs under the age of 18. These include:

- **Cissbury Lodge (Worthing)** – residential home for eight to 18 year olds with learning and physical difficulties. Provides both short and long-term care.
- **High Trees (Crawley and Horsham)** – provides residential or daytime short breaks for up to six children with severe learning disabilities aged between seven and 18 years.
- **Orchard House (Cuckfield)** – respite unit for children with learning disabilities aged 10 to 18 years, and day service provision for children under the age of 12.
- **Chailey Heritage Residential** is designed for young people aged between three and 19 years with complex physical disabilities and health needs. It offers flexible boarding packages including termly, weekly, fortnightly, and 52-week care, as well as short breaks and holiday activities.
- **The Finches** – short-term respite care in a purpose built bungalow in Burgess Hill for children and young people aged from birth to 19 years with a complex disability or health needs.

For further information on these or other residential respite services, contact your local Child Disability Service.

**Short Breaks for children with life-threatening illnesses**

**Chestnut Tree Community Team**

Chestnut Tree House near Arundel has a team of nurses and care support workers who provide support to families of
children with life-limiting or life-threatening illnesses at home and in the community. Types of support includes: at home care in order for you to take a break; clinical nursing care; overnight respite care for your child at the hospice; end of life care, pre and post-bereavement support.

They also run a number of fun days and activities at the hospice itself that children receiving community support are eligible to attend.

**Rainbow Trust**

Provides Family Support Workers to families of children with life-threatening or terminal illnesses. Support at home can include: helping with practical tasks at home; spending time with your child or their siblings; helping children remain in school by assisting with transport, and so on. They can also support families of children who are in hospital.

**Sussex Snowdrop Trust**

Provides care at home to children with life-threatening or terminal illnesses. The trust’s catchment area runs along the coast from Chichester to Littlehampton and as far north as Billingshurst. The Care at Home Team is based at the Westhampnett Centre in Chichester. Children are usually referred directly from hospital.

**Equipment and adaptations**

If your child has severe physical difficulties that make it hard to manage everyday things, such as mealtimes, toileting, or getting around, they may need additional support and facilities at home to help with daily living. These needs may change as they grow older or their circumstances change.

In West Sussex there are specialist occupational therapists (OTs) to assess children and young people with a permanent and substantial disability. You can contact the team via the Adult CarePoint on: 01243 642121 or email: socialcare@westsussex.gov.uk.

OTs can help parent carers by providing advice, and support, and equipment where needed, to help children and young people
Help with daily life

with special needs and disabilities maximise their independence, wellbeing and their dignity at home. Note that the waiting time for assessment varies, based on demand and also on the number of urgent referrals received.

Individual needs can vary greatly, so OTs offer specialist functional assessments at home to work out how difficulties can be overcome and independence can be maximised. The types of things an OT will look at include: accessing the home and garden; getting in and out of bed; seating; washing and dressing; toileting; and bathing/showering.

Once individual needs have been identified the occupational therapist will offer advice and information. They may also provide equipment to meet the assessed needs.

Community Equipment Service

After the assessment, some things such as toilet seats, grab rails, hoists, bath aids and temporary ramps may be prescribed to you by the OT and will be supplied by the Community Equipment Service. It will be delivered to you and, if necessary, safely fitted. You can also access community equipment through your GP, physiotherapist or community nurse.

Choosing Equipment

There are constant changes and developments in the kind of equipment and gadgets available. If large expensive items are recommended, make sure you try them out before making a decision: you need to see how they would work in your own home. Don’t be rushed or rush your child into making a decision and make sure you listen to what your child is telling or showing you. For example, if your child is terrified or experiences pain being lifted by a hoist, alternative slings or equipment may need to be considered.

If an assessment identifies that your child needs certain equipment, and they receive Direct Payments, you should be given the option to use them to buy what they need. Sometimes,
it is possible to top up the Direct Payment yourself to buy a more expensive piece of equipment, so long as it still meets your child’s needs.

The Disabled Living Foundation website has a dedicated section for children. It covers everything from clothing to communication and transport and also has information on specific conditions and advice on how to get grants. Go to: www.livingmadeeasy.org.uk/children.

It can also be worth going to one of the annual exhibitions for equipment. In the south of England this is called Kidz South, which is held in Reading. It has over 120 exhibitors offering information on: mobility; seating; beds; communication; education; toys; transport; sensory issues; funding and sports. For further information visit: www.kidzexhibitions.co.uk/kidz-south. Kidz exhibitions are also held in the Midlands, North of England and Scotland.

Wheelchair Service

If you need a wheelchair for your child you can get one on loan from the West Sussex Wheelchair Service, which has branches in Bognor, Horsham, and Worthing. You will need a referral from a healthcare professional, such as your GP or physiotherapist.

Specialist equipment

For specialised equipment, Chailey Heritage has a rehabilitation engineering unit, which will custom-make or specially adapt existing aids to suit your requirements. Others like REMAP and MERU will try to make equipment to suit your child’s individual needs, which you may not be able to get anywhere else.

Whizz-Kidz is a charity that can often help with financial costs where, for example, you’d like your child to have a better wheelchair than can be provided on the NHS. Whizz-Kidz may be able to make up the difference in cost if you can’t afford it yourself.
If your child needs specialist equipment at their childcare setting or school, you should discuss this with them.

**Adaptations to your home**

An adaptation is a change or changes to a property that mean a disabled person can move more freely and independently around their own home.

Examples of adaptations include widening doors or installing a stairlift, through to installing wet rooms and specially adapted bedrooms. Adaptations may be made to a home that is owned, rented from the council or from a private landlord.

If you need adaptations to your home, funding may be obtained through a Disabled Facilities Grant (DFG). Any work carried must be considered essential and not just desirable. It’s important to note that you cannot get a grant for work that has already started.

The maximum amount that can be awarded is £30,000, but Disabled Facilities Grants are NOT means tested for families of disabled children under 19 who are in full-time education. Once a formal application for a DFG has been received by a local authority, they must make a decision within six months.

Although most local authorities ask for an assessment from an OT or social services to help them decide if the work is ‘necessary and appropriate’ to meet your disabled child’s needs, it is possible to make the application for a Disabled Facilities Grant while you wait for an OT visit and assessment. Your local authority will have a form that you can fill in or you can apply by writing a letter. There is more detailed advice on applying for a Disabled Facilities Grant, as well as adaptations and equipment on the Contact a Family website: www.cafamily.org.uk.

**Moving home**

It may be that your present home isn’t suitable and can’t be adapted to meet your child’s needs. If you are a council or
housing association tenant you should speak to your housing officer about moving to a more suitable home. Occupational Therapists from social care can provide advice on rehousing and potential adaptations to properties being considered.

Although it’s often a long wait, if you need specially adapted accommodation you will have a better chance of moving, or your name can be passed to another housing association that has appropriate flats and houses. If you rent your home from a private landlord it can be even more difficult to make it suitable for your child’s changing needs. Your local council housing service can give you information about getting onto the council or housing association waiting lists. They may also know about local estate agents who have information about adapted properties for sale in the area.

Other kinds of practical help

This section includes a range of other schemes that can help with day-to-day living. For information about the schemes which primarily offer financial help, such as Motability and Family Fund, see chapter five. For the Compass Card leisure discount scheme, see page 138 in Chapter 9.

Carers Emergency Alert Card

This is a small card with a message that reads, ‘Someone depends on me. In an emergency please telephone...’. The number notifies the 24-hour emergency alert service, which will respond according to the instructions you leave on the enrolment form when you sign up. In West Sussex the scheme is managed by Chichester Careline. Contact them on: 01243 778688, or email: chichestercareline@chichester.gov.uk.

Continence support for children and young people with additional needs

If your child or young person has ongoing continence or toileting issues, you can ask for support from tier 1 services – usually the school nurse or health visitor in the Healthy Child Programme – and an appropriate toileting plan can be put in place for them.
After these strategies have been put in place, they will be reviewed by the health professionals. If progress has not been made they can refer your child on to the tier 2 specialist Children’s and Young People’s Continence Team. This can be accessed by children aged between three and 19 years. Referrals are accepted for:

- Constipation and soiling: age three and up.
- Toilet skills assessment: age three and up if a child has an identified additional need.
- Day wetting: age four and up.
- Night wetting: age five and up.

To contact the Continence Team call: 01273 242145 or email: sc-tr.childrenscontinence@nhs.net.

Getting out and about

Those of us who have children with complex needs have to plan outings, even simple everyday ones, with care. A trip to the supermarket can present problems if your child uses a wheelchair or large buggy. Your local council produces leaflets about access, which can be a useful starting point. They have details of a range of accessible places locally, including disabled toilets. They are also useful if you want to find out which branch of your bank has a ramp, for example.

Your local council will also have information available on disability access in your area. RADAR keys, which are used to open accessible public toilets as well as certain play equipment in inclusive play areas, are also available from your local council offices.

Fully accessible toilets

If your child or young person needs an adult-sized changing bench and/or hoist, toileting on the go can be very challenging. Thanks to campaigning, there are now more fully accessible toilets with these facilities, although many more are still needed. You can see what is available both in West Sussex and other areas, and follow the campaign by going to the Changing Places website: www.changing-places.org.
Disabled parking bay scheme

If your child has problems with mobility and has a Blue Badge – see page 43 for details – you may be eligible for a disabled parking bay outside your house, as long as you do not already have off-street parking. It’s important to note although it will be outside your house, the parking bay is available for use by anyone who has a Blue Badge. To apply, go to: www.westsussex.gov.uk and search for ‘disabled parking bay’.

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.

Passes are issued by West Sussex County Council. For more information on eligibility criteria 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 0845 075 1018 or email buspass@westsussex.gov.uk.

Community and rural transport

West Sussex county council provides a list of organisations that provide transport for people with disabilities. This includes: community car and dial-a-ride schemes; community buses accessible to wheelchairs; special taxis; and local offices of Shopmobility.

National train travel

The National Rail Enquiries website provides information for disabled passengers about accessibility, train operating companies, accessibility maps that show which stations have lift access to platforms and information on staffing levels. Go to: at www.nationalrail.co.uk or call: 0800 022 3720 to arrange for assistance on a train journey.

You can also access information about train travel at: www.disability-onboard.co.uk.
It has advice on booking assistance, as well as contact numbers for local train services.

**Disabled person’s railcard**

If you do not wish to have a Disabled Person’s bus pass, you can apply for a Disabled Person’s Railcard instead. While the railcard doesn’t offer discounts on child fares, it will allow one person travelling with the cardholder to get a third off most rail fares. To check eligibility and apply go to: www.disabledpersons-railcard.co.uk.

**Access and mobility**

**Out of town**

For access elsewhere in the UK, go to: www.accessibleguide.co.uk, where you can download a free PDF of *The Rough Guide to Accessible Britain*. The guide contains more than 200 ideas for worry-free days out, with reviews, hints and tips on some of the UK’s best attractions written by and for disabled people. Each entry contains all the access information you need to enjoy your day including disabled parking, and wheelchair access.

You can also find information and reviews on many attractions at: www.disabledgo.com.

**London**

The Transport for London (TfL) website, https://tfl.gov.uk, offers information about accessibility to help people plan their journeys. They also have a number of accessibility guides that give details of step-free stations, lifts, accessible toilets and other useful information covering tube, bus, river taxis and other forms of transport in the capital. Guides can be downloaded in PDF, large print and audio format from the TfL website.
Having a child with SEND often means that our family life is very different to the one we had imagined and it can bring extra pressures.

When you have to make time for endless appointments, phone calls, or therapy sessions, it is very hard to find the time for ordinary things, especially if you have other children. At first, many of us find it difficult to get any sense of normality. But we realise how important it is to try to do things as a family.

‘You have to realise that this is just one child in your family, and you are a family and you all count – each one of you counts. You focus so much on your SEND child that everyone else goes out of the window, and it’s getting a sense of proportion again.’

Not everyone has a traditional nuclear family. As well as our child’s condition, some of us also have to deal with the isolation of being a single or lone parent. This can be especially hard if your child’s condition is one that makes it difficult to ‘fit in’.

We know that getting out and about can be extremely difficult. You may feel worried about lots of aspects including: how to get there; whether your child will be accepted; how to deal with problems and also how to deal with people being judgemental about your child and their condition, especially if it affects their behaviour.

However, finding social activities that your family can enjoy can help restore normality. Most of us have found places where everyone can join in – the local swimming pool, park, local farms, zoos, or quieter beaches where you and your family won’t have to worry about what others think.

Often, parents who have children with similar conditions to yours
are easier to be with, as they understand the challenges and you don’t have to explain. It’s also helpful to be able to chat to other people in a similar position so you can share ideas and tips.

‘We usually go to Drusillas. I feel sorry for my oldest sometimes, because he’s almost like an only child; he really wants someone along to play with. So we always take his cousin with us. They get on brilliantly together and she’s also brilliant with Alex, my child who has additional needs, and it’s so lovely to see her included as well, instead of just being ignored.’

Choosing leisure activities

Like everyone else, children with SEND want to have a social life and take part in activities they enjoy. But, as a parent, you want to know that they will be welcome, safe, and supported. And if you have other children it’s important that they can enjoy themselves, too.

When you are thinking about new activities you may have lots of questions. Do the people running the activity have prior experience of children with SEND? Do they understand what difficulties there may be, and how will they make sure my child can access the activity? What will happen if my child has a meltdown? Is there a safe place to let off steam? What are the rules? Are they fair and make sense to children? What’s in place to help a child deal with disappointment? Will my child be encouraged to do as much as they can for themselves but not left to struggle with things they can’t manage? Will they have appropriate boundaries in place?

Sometimes, the easiest way to find out is to sit in on a session to see how it is run. Written policies are fine, but what happens in practice is more important. Also, ask other children, young people and parents what they think. Their views might offer different perspectives that enrich your impressions.

Don’t dismiss a club because parents are required to stay. Some of the best activities are organised by other parents and volunteers who cannot take responsibility for supervising children who need the toilet or want to sit out for a bit.
Sometimes, you have to balance the value of a free or inexpensive opportunity for your child against the chance to have a break yourself. These are often the places to meet other parents and exchange advice and support.

It’s also worth asking the organisers if they offer a ‘taster’ session, as many do. This can be really helpful and many of us have found that this has encouraged us to try activities that may be completely new to us and our children.

Once they’ve tried a session ask your child how it went and listen to them – you are the expert at ‘reading’ your child, no matter how they communicate. If you sense that they have not enjoyed an activity, don’t give up. You may have to try a few before you find one that your child takes to.

**Compass Card**

The Compass Card is a leisure discount scheme for children and young people aged 0 to 25 years with SEND. You can use the card to get discounts and special offers in leisure venues across West Sussex, and for selected organisations in Brighton and Hove and East Sussex, too. There are more than 150 offers, and leisure partners include organisations such as Lodge Hill, Albion in the Community, leisure centres, cinemas and other local attractions.

The scheme is run in West Sussex by Amaze Brighton and was launched in 2016. To get a card, you must be added to the disability register, which all local authorities have a duty to keep. The register helps to plan which services are needed within the county.

You can also use your Compass Card as a library card in West Sussex. To find out more about the scheme and fill in an application form at: www.compasscard.org.uk.

**Local activities**

This section lists some of the activities that we have found to be inclusive and open to all. Some have been set up where
children with and without SEND can have fun together, others are specifically for children and young people with additional needs.

All children are different, so it is advisable to contact these groups yourself so that you can get more information and decide whether the activity is suitable for your child and something they might enjoy.

**Babies, toddlers and under-fives**

Your child will probably enjoy many of the mainstream activities available locally for this age group, such as toddler groups, soft play centres, music groups and gym clubs.

The Family Information Service has details of a range of toddler groups in the county.

Families can also borrow toys from their local libraries and some Children and Family Centres also lend out sensory toys. Go to: www.westsussex.gov.uk/toylibraries to find out more.

‘Something I do with Jane, and I’ve found it has been absolutely brilliant, has been a music group – it’s for under-fives and she loves it!’

There are several projects and facilities available to young children with SEND in West Sussex, including:

**Bookstart:** a national programme that encourages parents to read with their children. Bookstart Baby is a pack containing two books and a rhyme sheet. Usually it is given to parents by health visitors at their baby’s six to eight week check, or you can ask for one at your local library. Bookshine and Booktouch are special packs with touch and feel/audio books for babies with sensory impairments. These are available through your local library.

When your child is three, he or she will receive a Bookstart Treasure pack, with two picture books, colouring pencils and a mark-making book. These are available through your child’s nursery, pre-school or playgroup, or your local library.
Chanctionbury Impulse Leisure Centre runs birth to five years inclusive soft play on Saturdays. Also has a fully accessible toilet. Tel: 01903 746070.

Early Years hubs: eight of the 44 Children and Family Centres in West Sussex are also Early Years Hubs, which offer additional services, advice and activities specifically for children with SEND, including ‘Play and Learn Plus’ sessions. Some hubs also have sensory areas for children to access as well as sensory toys.

The hubs are based at: Bognor Nursery School and CFC; Boundstone Nursery School and CFC (Lancing); Chichester Nursery School and CFC; Durrington CFC; East Preston CFC; Horsham Nursery School and CFC; Langley Green CFC (Crawley); and Sidney West CFC (Burgess Hill). For contact information, see Essential contacts page 155.

Gym Joeys (Bognor Regis): pre-school gymnastics to help children develop gross motor skills. Welcomes children with additional needs. Classes are held in Bognor, Chichester, and Littlehampton. Tel: 07799 836341.

Kangaroos (Haywards Heath): runs monthly Saturday ‘stay and play’ sessions for children aged up to five years who have additional needs, including those without a formal diagnosis. Sessions alternate between Burgess Hill and Haywards Heath. For more information and to book a place, email: lorna@kangaroos.org.uk.

Local libraries: you can register your child for their own library card as soon as they are born. Many libraries offer baby and toddler activities, such as rhyme time and story time, and also have a toy library. You can find your nearest library in the Local Directory at the back of the book.

Pavilions in the Park (Horsham): runs inclusive parent and baby and parent and toddler sessions. Tel: 01403 219200.

Springboard Project (Horsham and Crawley): both centres run a monthly group called ‘under 6’ for young children with SEND,
on a Sunday afternoon. They also run ‘play ‘n stay’ groups for all families, and have a toy library. Tel: 01403 218888 (Horsham) or 01293 531963 (Crawley).

SNAPS (Worthing): is a special needs parent and toddler group that meets on the first and third Friday in the month during term-time. Tel: 01903 207024.

School age children

With preparation, some children are able to join organisations such as Brownies or Cubs. Many of these groups will have advisers who can help you find a suitable pack for your child.

Joining a new club can be daunting, especially for children who look different, have difficulty making themselves understood, or struggle to understand new situations. Talk to the staff about how your child can be helped to feel comfortable. Your child might want to think about how they would like to be introduced and whether they’d like to do this themselves. They might find it helpful to go along with a companion to help them join in.

There are other local activities which your child might enjoy if planned carefully. There are also activities which are specially set up for children with SEND, as well as inclusive activities, which welcome all children. Many of our children have enjoyed integrated summer playschemes or social, sports or arts clubs. Sometimes, the whole family can join in, at others our children are able to make friends away from us.

The following pages include some suggestions that may suit your child. Activities marked (SB) are short breaks providers – see page 123 for more information on short breaks, eligibility criteria and how to access them. You can find out more by calling the Short Breaks Team: 0330 222 2562, or emailing: short.break.team@westsussex.gov.uk

Activities shown below are also listed in the Local Directory, where you can find additional contact information including email addresses and websites, where available.
6 – 12 (SB) is run by the Springboard Project for six to 12 year olds with SEND in Crawley, Horsham and Worthing. Offers a term-time Saturday Club, as well as activities in the school holidays. Tel: 01403 257699 (Horsham and Worthing) or 01293 542821 (Crawley).

Adur Special Needs Project (Shoreham) runs various playgroups and clubs for five to 15 year olds with SEND in Shoreham and surrounding areas. Tel: 07788 239634.

Albion in the Community (SB) (Brighton) runs inclusive sports sessions for young people as well as disability specific clubs and clubs for wheelchair users. Tel: 01273 668590.

Angling4Education (SB) delivers fun educational holiday and weekend provision around fishing and the environment for young people with SEND and their families. Tel: 07795 410812.

Ariel Othello’s (Burgess Hill) Saturday dance, drama, music, and singing for children and young people with special needs. Juniors for children aged 7 to 19 and Adults for those aged 16+. Tel: 01444 250407.

Ashdown Club (Worthing) (SB) runs weekly and holiday clubs for children aged five to 12 and a youth club for young people aged 12 to 18. Open to children with SEND. Tel: 01903 528607, email: ashdown@guildcare.org.

Autism Sussex (SB) provides outreach 1-1 support, short breaks and various clubs for children and young people with autism across Sussex. Tel: 0345 450 0060.

Billingshurst Leisure Centre (SB) runs weekly swimming lessons for children, including those with disabilities. Pool has a hoist. Tel: 01403 787500.

Broadbridge Heath Leisure Centre (Horsham) (SB) runs Discovery Fun Days for disabled children, their families and friends. The activities include: a bouncy castle; trampolining; sports; arts and crafts; as well as use of their purpose-built sensory room. Tel: 01403 211311. Email: enquiries@ broadbridgeheathleisurecentre.co.uk
**Brooklands Leisure Park** (Worthing) has an inclusive playground for children and young people. The wheelchair swing can be unlocked with a RADAR-key. Also has a purpose-built cycle track and specialised bikes for hire.

**Chanctonbury Community Playscheme (SB)** a volunteer-led playscheme that runs for four weeks in three West Sussex venues during the summer holidays. Open to children aged five to 19 years with an EHC Plan or Statement of SEN. For information and an application form, call: Hannah Mackerell on: 07455 131462 or email: ccpsorganiser@gmail.com.

**Charlotte’s Tandems** volunteers loan tandems and tag-alongs to people with SEND who are unable to ride a bike safely on their own. Includes accessories such as helmets, if required. www.charlottestandems.co.uk

**Cobnor Activities Centre** (Chichester) water activities centre for anyone with a disability. Tel: 01243 572791

**Crawley BMX Track** is an inclusive track that has specially adapted bikes and part-time instructors. Tel: 01293 585350.

**Dome Cinema** (Worthing) holds autism-friendly screenings on the second Saturday of the month. Siblings welcome, too. Parent carers must attend. Tel: 01903 823112.

**Drusillas** (Alfriston, East Sussex) is a small zoo with other entertainment and activities for children. It also participates in the annual Dream Night event in June, a free evening for severely ill or disabled children. Tel: 01323 874100.

**Ferring Country Centre** (Worthing) riding lessons/therapy for children and adults with physical and learning disabilities. Tel: 01903 245078.

**Flamingoes Club** (Crawley) is a swimming club for people with physical disabilities. Meets at K2, Crawley, every Tuesday. Tel: 01293 882148.
**Forest Flyers** (Horsham) runs football coaching for seven to 18 year olds with disabilities. Meets every Saturday at Forest School. Tel: 07715 320631

**Freedom Leisure** (K2 in Crawley) recreational play, sports activities and swimming lessons for anyone of five years and over with special needs/disabilities. Also holds family fun days. Tel: 01293 585300.

**Gaston Farm** (Slindon) for lambing in the spring and shearing during the summer half-term (June). Offers tractor and trailer rides, has disabled parking and is wheelchair accessible. Tel: 01243 814269.

**Guides Association** has around 20,000 members with additional needs. Offers grants for special equipment or support to help girls access activities. Go to: www.girlguiding.org.uk, click on ‘information for parents’ then select ‘support for additional needs’.

**Gully’s Days Out** is a scheme run by Albion in the Community, which allows members to get free passes to a host of different attractions including: Arundel Wetlands; Brighton FC; Cineworld; Inspire Leisure; Ocean View Diving Centre; and the Sea Life Centre. Tel: 01273 668590.

**Hack Horsham** runs regular inclusive STEAM (Science, Technology, Engineering, Arts, Maths) workshops and events where children and young people can work on everything from Minecraft to coding and simple circuits. www.facebook.com/hackhorsham www.hackhorsham.org.uk

**Horsham District Sports Development (SB)** runs the Reaching Higher Project – weekly term time after-school short breaks for children over 5 years with SEND. Activities include: dance; percussion; video production; archery; badminton; cricket; inclusive cycling; rebound therapy; table tennis; and wheelchair basketball. Tel: 01403 215631 or 07715 320631

**Horsham Park** has a wheelchair swing, which can be unlocked with a RADAR-key. A fully accessible Changing Places toilet is also available at the adjacent Pavilions in the Park.
Impulse Leisure (SB) runs rebound therapy and family fitness sessions. Tel: 01273 238000 (Shoreham, Wadurs), or 01273 238111 (Southwick).

Kangaroos (SB) after-school clubs, weekend and holiday playschemes for children (aged 6+) and young adults with SEND. Activities are tailored to ages and abilities. Main clubs: PALS, STARS, BreakAway, No Limits. After-school and evening clubs: AllSports, Champions, TeenScene, Youth Club, Social Club. Tel: 01444 459108

KIDS (SB) short breaks to help disabled children aged 6 to 18 years in the Chichester area to go out into the community and access groups. Tel: 01329 312312.

Lodge Hill (Pulborough) accessible lodges and an activity centre that includes facilities for disabled people. Tel: 01798 831411.

Mid-Sussex Marlins (Burgess Hill and Haywards Heath) a swimming club with two groups for children and adults with disabilities: Dolphins (Burgess Hill) and Starfish (Haywards Heath). Email Pauline at: dolphins@midsussexmarlins.org or Carolyn at: starfish@midsussexmarlins.org.

Mohair Centre Holiday Workshops (Lewes, East Sussex) a working farm offering a holiday playscheme, after-school club and nursery, able to include children aged up to 11 years with additional needs. The centre is near Chiddingly, Lewes. Tel: 01825 872457.

Moving Barriers Club (Crawley) runs sports and activities for children and young people aged six to 25 with disabilities living in or near Crawley. Meets every Friday at K2, Crawley. Tel: 01293 585350.

MXT Swimming School (Chichester, Storrington, and Steyning) has swim teachers experienced in working with children with autism, muscular dystrophy, ADHD, dysphasia, dyspraxia and cerebral palsy. Tel: 01903 202700 or 07903 731370.
National Autistic Society West Sussex Club (Horsham) for five to 18 year olds with autism or Asperger’s, held on Thursday evenings at Lavinia House, Horsham. Tel: 01483 521743.

PACSO (Chichester) (SB) runs a number of after-school clubs, weekend activities, and holiday playschemes for children with SEND aged from birth to 25 years. Tel: 01243 533353.

Pavilions in the Park (Horsham) runs swimming lessons for children aged between five and 18 years. Tel: 01403 219200.

Phoenix Centre (Bognor) offers a fully equipped sensory room for children and adults with SEND. Includes bubble tubes, sensory boards and mats. Tel: 01243 840075.

Riding for the Disabled has groups in Arundel, Chichester, East Ashling, Lingfield, and Slinfold. Tel: 01926 492915.

Scouts Association for information on local Cubs and Scout groups. Tel: 0345 300 1818.

Southern Area Disability Sports Group (Worthing and Adur) runs sporting activities for children and young people with disabilities aged between five and 16 years. Tel: 01903 778328.

Steyning Leisure Centre provides swimming lessons for disabled children aged between five and 18 years. Tel: 01903 879666.

Sunbeam Swim Club (Horsham) is a weekly swimming club for disabled people of all ages. Tel: 01403 253200.

Sussex Cricket Club holds weekly cricket sessions and holiday camps in Chichester, Horsham, and Worthing. Tel: 0844 264 0203.

Sussex Otters Swimming Club (Chichester) is a swimming club for children and adults with disabilities. Tel: 01243 781259.

Sussex Wasps (Brighton) is a sports club for people with disabilities. Activities include: javelin, discus, bowls, archery, wheelchair basketball, tennis, table tennis and track events. Tel: 01273 701235.
**Time Aside (SB)** runs sensory art workshops for health, esteem, and communication needs. Held at various venues. Tel: Sueloo on 07792 903236.

**Westgate Leisure Centre** (Chichester) various sports and leisure activities, such as inclusive swimming and trampolining for children aged five and over, as well as Branching Out, a club running sports and activities for children aged 2 to 18 with SEND and their families. Tel: 01243 785651.

**Worthing Lego Club** for children and young people with additional needs and their families. Held on the last Saturday of the month at St John’s Church Hall, Worthing. Tel: 07538 375936 or visit: www.facebook.com/worthing.lego.club

**Worthing Leisure Centre** runs various sports and leisure activities for children and young people with disabilities, including trampolining. Also runs Special Olympics athletics for anyone with SEND aged eight and above every Tuesday from 5 p.m. to 6 p.m. For trampolining, tel: 01903 502237. For wheelchair racing and Special Olympics, tel: Claire Moyle on 07762 013949.

**YMCA East Surrey (SB)** runs Yippee, a playscheme in school holidays for five to 11 year olds in the Crawley area. Tel: 01737 222859

‘I try to let Christina do the things that ordinary children take for granted – I try to make it possible for her to go to the park, we do swimming and we go horse-riding every week when she’s on holiday.’

**Teens and young adults**

Many of the suggestions we have made for school-age children also cater for young people up to 18 years of age and some up to 25 years. Older children, even those with very complex needs, often thrive on integrated adventure and activity holidays. Many of the local parent-run disability groups arrange social and play activities. The following includes a few more ideas.
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.

Blue Oasis Clubs holds club nights, autism-friendly film screenings and outreach for young people and adults with learning disabilities and their friends. Crawley/Horsham tel: 01403 215216; Worthing tel: 01903 221017. Email: blueoasishorsham@gmail.com.

Carousel (Brighton) runs inclusive creative arts projects and groups for young people 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.

Ready and Able (Horsham) is a weekly social club for disabled people aged 16+ that meets at Christ’s Hospital Sports Centre in Horsham. Tel: 01403 215637.

Sussex Sonics Wheelchair Basketball Club (Brighton) is a wheelchair basketball club for people with disabilities. Tel: 01273 307505.

Sussex Wasps (Brighton) is a sports club for people of all ages with disabilities. Tel: 01243 701235, or email: archerphil@ntlworld.com.

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.

12 – 18 (SB) is run by the Springboard Project for 12 to 18 year olds with SEND in Crawley, and Horsham. Offers weekday evening activities and a holiday scheme to help young people build life skills. Tel: 01403 257699 (Horsham) or 01293 542821 (Crawley).

18 – 25s (SB) is run by the Springboard Project for 18 to 25 year olds with SEND in Crawley, and Horsham. Tel: 01403 257699 (Horsham) or 01293 542821 (Crawley).
Autism Sussex (county-wide) provides a buddy scheme for 0 to 19 year olds with autism. Tel: 0345 450 0060 (ext 114), email: childrenesx@autism sussex.org.uk www.autismsussex.org.uk.

Grace Eyre Foundation runs a friendship scheme for young people with disabilities. Tel: 01273 201900

Orchard Connect (SB) runs groups for young people aged 11 to 18 years with SEND. The Youth Club meets every Thursday in Burgess Hill. Also runs Monday club in school holidays. Booking is essential – please do so via email. Tel: 01444 454226, email: martin.norris@westsussex.gov.uk.

SASBAH (Sussex Association for Spina Bifida and Hydrocephalus) runs a buddy scheme for young people in West Sussex. Open to all disabilities. Tel: 01825 873045

Stay Up Late is a charity providing support to people with learning disabilities aged 18+, including buddies to accompany young people to gigs. Tel: 01273 468168

YMCA East Surrey (SB) runs term time and school holiday club Yip4Youth for 12 to 18 year olds in Horsham and Crawley. Tel: 01737 222859.

Other leisure ideas for all ages

Local

There are a number of nearby places that we have found very enjoyable for our children and for a day out with the whole family such as: Drusillas Zoo, Alfriston; Fishers Farm, Wisborough Green; Tilgate Park, Crawley; the Wildfowl and Wetlands Trust, Arundel; and Washbrooks Farm, Hurstpierpoint.

Regular autism-friendly screenings take place at various cinemas around the county. Lights are left on low, the sound is turned down and the audience is free to get up and move about as they please. It’s a great way of introducing any child with SEND to the delights of going to the cinema.
If your child is interested in sports activities, the English Federation of Disability Sport is a one-stop shop for information about different sports opportunities for disabled children and adults. Go to: www.efds.co.uk to find out more.

It is also worth joining your local library. As well as borrowing books and DVDs, you can also access activities including holiday reading challenges and some larger libraries also hold regular sensory story sessions for children with SEND.

If your child has communication needs, you may be interested in West Sussex library’s communication library, Understand Me, which has free resources to borrow including flashcards, recording devices and other resources to support people who use Alternative and Augmentative Communication (AAC).

You can find contact information for your local library in the Local Directory at the back of the book.

**National**

Letterbox Library is a book club that specialises in multi-cultural books. They also have a selection of books that feature children with SEND as characters.

Listening Books is an audio book library for children and adults who find reading difficult because of illness or disability. Readers pay a membership fee and can access titles as downloads, via streaming or as MP3 CDs. The local library service in West Sussex also offers this free of charge.

If you’re going away, take a look at The Rough Guide to Accessible Britain, which has ideas for more than 200 days out. Go to: www.accessibleguide.co.uk, where you can download a free PDF.

It’s also worth contacting organisations in the area you’re visiting to find out what’s on offer for children with SEND. Contact the visitor information offices for information on things such as accessible toilets.

Many of the larger theme parks such as Legoland and London Zoo offer concessions and also
organise special days for disabled children and their families, so contact them directly for details.

In London, Artsline has information about disabled access to more than 1,000 venues, and also about special events and activities for disabled children.

**Holidays**

We all feel in need of a break every so often, but sometimes the thought of all the planning makes it seem too much effort.

There are several organisations that can point you in the direction of places that will be accessible and welcoming to everyone, whatever their needs. Tourism for All has travel advice and transport information for disabled people and can help you plan your journey. It also has a lot of information on all kinds of family holidays, as well as holidays for children with SEND without their parents.

Contact a Family has a guide to holidays, play and leisure activities for families of children with SEND.

The 3H Fund runs subsidised group holidays for physically disabled children. Happy Days charity also funds and organises holidays and days out for families with children with SEND aged between three and 17 years.

The Disabled Go website also provides up-to-date information on accessibility at many public venues and holiday accommodation throughout the UK.

Increasingly, more travel agents are able to provide better information on facilities for disabled people, as they begin to realise there’s a big market out there. You need to ensure your child’s needs will be catered for, and it is worth asking for these arrangements to be confirmed in writing when you book. It’s amazing how many people still think that an entrance up half a dozen steps is accessible for a wheelchair user!

You should also make sure that any insurance you take out is appropriate – in the small print you might find that ‘pre-existing conditions or illnesses’ are not covered. If that’s the case, there
are policies that are better and you can find out about them from organisations such as Tourism for All, or Cerebra.

‘It has taken me quite a bit of time to adjust to the need to do all this preparation, but then it’s been worth it because it’s made our holidays easier and I’m less stressed.’

**Gatwick airport**

If you are flying with a person with SEND, it does require some extra planning before you go. If your child is a wheelchair user or has reduced mobility, it essential to request special assistance before you travel. It is best to do this via your airline or travel agent when you book your tickets. Special assistance must be requested at least 48 hours prior to your journey.

If you require an eagle hoist to transfer your child from their wheelchair to their plane seat, this should be booked at least 24 hours before you travel by emailing: eagle.hoist@ocs.co.uk.

Gatwick airport also has a fully accessible Changing Places toilet in each terminal and has announced that two more fully accessible toilets are planned. It is also looking to build a sensory room in each terminal.

Recently, Gatwick Airport launched their ‘Hidden Disability Assistance Programme’. It is available to anyone with autism or other hidden disability who needs extra support and understanding at the airport. The service can provide special lanyards, which are available from their assistance desks. These identify the wearer as someone who needs additional support from staff. The website also has a link to a booklet, entitled *Making Your Journey Easier*, with information, advice and photos of different parts of the airport.

If your child has autism, you can also print off a visual planner to use during your journey. For more information, email: hidden.disability.at.gatwick@ocs.co.uk.

You can find out more about the full range of assistance available at: www.gatwickairport.com. Choose ‘passenger services’, then ‘special assistance’.
Reaching Families * AFASIC * Independent specialist provision * National Autistic Society * Family Fund * SNAPS * special schools * Muscular Dystrophy UK * PATH * Benefits Advisor * Asthma UK * Carers Support West Sussex * Rainbow Trust * Winston’s Wish * Cerebra * SWAN UK * BIBIC * Children’s and Young People’s Continence Team * Motability * SENDIST * Contact a Family * Whizz-Kidz * Relate * Scope West Sussex * Ashdown Club * Council for Disabled Children * Carousel * Disabled Living Foundation * Down’s Syndrome Association * SANDS * Social Communication Team * Early Years Hubs * Albion in the Community * Children and Family Centres * Fragile X Society * West Sussex Parent Carer Forum * Heartline * IPSEA * Kangaroos * SASBAH * Mainstream schools * Mencap * Blue Badge Scheme * Hemihelp * Children and Family Centres * WKDS * NASEN * PACSO * PALS * Chailey Clinical Services * physical disability units * Puzzle Pieces * RettUK * Riding for the Disabled * Citizens Advice Bureau * SEND Hub Networks * Headway * Wellspring * Portage * Child Development Centres * special support units * Autism Support Crawley * Gingerbread * speech and language units * SOS SEN * Challenging Behaviour Foundation * CLAPA * The Springboard Project * Sibs * Unique * Directories
Note: listings marked (SB) are Short Breaks providers.

**Action Against Bullying Support Line (WSCC young people services)**

Tel: 0333 014 2904, email: Michaela.homewood@westsussex.gov.uk

**Benefits Advisor (WSCC)**

Advice and support for people applying for welfare benefits, including DLA/PIP, for themselves or their children.

Tel: 0330 222 2569 or 07850 240874
Email: robert.hayes@westsussex.gov.uk

**Blue Badge Scheme (WSCC)**

If your child is in receipt of DLA (or PIP if over 16) you may be able to apply for a Blue Badge to help you to park.

Tel: 01243 777653
Email: blue.badges@westsussex.gov.uk
www.westsussex.gov.uk

**Carer’s Allowance Unit**

For information on Carer’s Allowance and how to make a claim.

Tel: 0345 608 4321, email: cau.customer-services@dwp.gsi.gov.uk

**Carers Emergency Alert Card Scheme**

Identifies you as a carer in the event that you have an accident or fall ill when you are away from the person you care for.

Tel: 01243 778688, email: chichestercareline@chichester.gov.uk
www.chichestercareline.org.uk

**Changing Places**

Changing Places are fully accessible toilets that have an adult sized changing bench, hoist and space for carers. See website for toilet locations and the Changing Places campaign.

Tel: 020 7696 6019, email: ChangingPlaces@mencap.org.uk
www.changing-places.org
**Child and Adolescent Mental Health Services (CAMHS)**

Referrals must be made by a professional from health, social care or education. To help you and your child understand what happens after a CAMHS referral is made, go to the second website below.

Tel: 0300 304 0100
www.sussexpartnership.nhs.uk/CAMHS
www.turnyourfrownupsidedown.org.uk

**Child Development Centres (CDCs)**

Chichester: 01243 793639
Crawley and Horsham: 01293 600351
Haywards Heath: 01444 414100
Worthing: 01903 286700

**Children and Family Centres (CFCs)**

Centres marked ‘*’ are Early Years Hubs, offering additional services, advice and activities specifically for children with SEND.

Angmering: 01903 276894
Bewbush: 01293 651760
Billingshurst: 01403 213594
Bognor Regis*: 01243 642924
Bognor (Treehouse): 01243 642917
Broadfield: 01293 651777
Burgess Hill (Sidney West)*: 01444 255493

Burgess Hill (The Gattons): 01444 255480
Chichester*: 01243 642950
Crawley (Langley Green)*: 01293 651747
Durrington*: 01903 276888
East Grinstead (Blackwell): 01342 332992
East Grinstead (library): 01342 332970
East Preston*: 01903 270470

Felpham: 01243 642882
Findon: 01903 270455
Fishersgate (Stepping Stones): 01273 467980

Haywards Heath: 01444 255499
Horsham*: 01403 224444
Horsham (Roffey): 01403 213575
Horsham (The Needles): 01403 213590

Kingston Buci: 01273 467998

Lancing: 01903 276898
Lancing (Boundstone)*: 01903 276850
Littlehampton: 01903 276840

Maidenbower: 01293 651720
Maybridge: 01903 276890
Midhurst: 01798 871199
Mid Sussex Rural North: 01444 255477
Northgate: 01293 651740
Petworth: 01798 871199
Pound Hill: 01293 651722
Pulborough: 01798 871194
Rural Haywards Heath: 01444 255477
Rural Henfield and Steyning (Cowfold): 01903 270444
Rural Horsham: 01403 785816
Selsey: 01243 642906
Southbourne: 01243 642953
Southgate: 01293 651798
Southwater: 01403 213570
Storrington (Little Footsteps): 01903 270444
Sussex Downs (Rural Burgess Hill): 01444 255477 or 01273 467968
Tarring: 07955 496559
Worthing (Footprints, Crescent Road): 01903 276807
Worthing (Footprints, Lyndhurst Road): 01903 270424
Worthing (The Wave): 01903 276869
Yapton (The Villages): 01243 642958

For further information go to:
www.westsussex.gov.uk/cfc

Citizens Advice Bureau

Provides free, independent, confidential and impartial advice on everything from benefits to money and debt, to housing, health, and law.

Helpline tel: 0344 411 1444
Consumer helpline tel: 0345 404 0506
www.citizensadvice.org.uk

Community Equipment Service (WSXCES)

Access to equipment is via a GP, occupational therapist, physiotherapist or community nurse. For delivery, collection, repair or servicing of equipment, contact NRS Healthcare

Tel: 0345 127 2931
www.sussexcommunity.nhs.uk/services

Disabled Go

Information on accessibility and other tips for thousands of venues across the UK and the Republic of Ireland

Tel: 01438 842710
Email: enquiries@disabledgo.com
www.disabledgo.com
Disability Living Allowance (DLA) (under 16s)

For people aged 16 and over, see Personal Independence Payment (PIP) see page 159.

Tel: 0345 712 3456
www.gov.uk/disability-living-allowance-children/how-to-claim

District and Borough Councils

www.westsussex.gov.uk/about-the-council/your-other-local-councils/district-and-borough-councils/

Adur – tel: 01273 263000, email: helppoint@adur-worthing.gov.uk

Arun – tel: 01903 737500
Email: info@arun.gov.uk

Chichester – tel: 01243 785166
Email: contact@chichester.gov.uk

Crawley – tel: 01293 438000
Email: comments@crawley.gov.uk

Horsham – tel: 01403 215100
Email: contact@horsham.gov.uk

Mid-Sussex – tel: 01444 458166
Email: enquiries@midsussex.gov.uk

Worthing – tel: 01903 239999, email: enquiries@adur-worthing.gov.uk

Family Fund

Grants for families of children with disabilities or serious illness. See website for eligibility criteria.

Tel: 01904 550055
Email: info@familyfund.org.uk
www.familyfund.org.uk

Family Information Service (WSCC)

West Sussex County Council service offering up to date information to families on activities, services and childcare.

Tel: 01243 777807, email: family.info.service@westsussex.gov.uk
www.westsussex.gov.uk/fis

Fun and Breaks (FAB) (SB)

Provides volunteers to help children and young people aged up to 18 to access activities and pursue hobbies. For more information, go to the web address below, click on ‘SEND’ and go to ‘Fun and Breaks’.

Tel: 01243 777100
Email: fab@westsussex.gov.uk
www.westsussex.gov.uk/education-children-and-families
Home-Start

Charity that supports families with young children, who may be dealing with issues such as post-natal depression, isolation and health problems. Their services include: home visiting, groups, and support so families can access other services.

Arun, Worthing and Adur:  
Tel: 01903 889707  
www.home-startarun.org.uk

Chichester: Tel: 01243 773477, email: admin@home-startchichester.org.uk

Crawley and Horsham:  
Tel: 01293 416327  
Email: info@homestartchams.org.uk

Independent Support (IS)

Provides parent carers with advice and support on EHC transfers and Annual Reviews for children and young people up to the age of 25. In West Sussex, IS is delivered by Amaze.

Tel: 0300 123 7782  
Email: is@amazebrighton.org.uk  
www.amazebrighton.org.uk/services-and-support/advice-sussex/independent-support/

Local hospitals with A&E departments

East Surrey Hospital  
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

Multi-Agency Safeguarding Hub (MASH)

Single point of contact for all safeguarding concerns regarding children and young people in West Sussex. Includes access to Early Help.

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

Email: england.contactus@nhs.net
www.nhs.uk

NHS England

Tel: 0300 311 2233
Email: england.contactus@nhs.net
www.england.nhs.uk

NHS Sussex Community (NHS Foundation Trust)

Tel: 01273 696011
www.sussexcommunity.nhs.uk

Occupational Therapy

Chichester: 01243 793641
Crawley CDC: 01293 600300 ext. 4049
Haywards Heath:
01444 414100, ext. 223
Horsham (Hilltop Centre):
01403 227000, ext. 7103
Worthing: 01903 286710

Out of Hours GP service

NHS non-emergency number
Tel: 111, free from landline or mobile.

Personal Independence Payment (PIP) (age 16 +)

For under 16s, see Disability Living Allowance, page 157.

Tel: 0800 917 2222 (new claims)
Tel: 0345 850 3322 (queries and existing claims)
www.gov.uk/pip/how-to-claim

Portage

A home-visiting educational service for very young children with significant support needs.

Tel: 01293 572480, email: sonia.maskell@westsussex.gov.uk
www.portage.org.uk/west-sussex-portage-service

SEND Information, Advice and Support Service (SEND IAS)

Tel: 0330 222 8555
Email: send.ias@westsussex.gov.uk
www.westsussex.local-offer.org/information/3-information-advice-ias

SOS SEN

Free, independent and confidential help for parents and others looking for information and advice on special educational needs provision. Phone line open Monday to Friday and Tuesday evenings.

Tel: 020 8538 3731, term-time only, www.sossen.org.uk
Sensory Support Team

Supports children and young people aged 0 to 19 years who have hearing, visual or multi-sensory impairments.

Tel: 01903 270430, email: sensory.support@westsussex.gov.uk
www.westsussex.gov.uk/education-children-and-families

West Sussex Local Offer

Local authority website providing information on SEND provision in West Sussex for families who have children aged from birth to 25 years with SEND. See page 8 for more information.

www.westsussex.local-offer.org

West Sussex County Council (WSCC)

General Enquiries: 01243 777100
Disabled Parking (Blue Badge): 01243 777653
Family Information: 01243 777807
Schools and Learning Service: 0333 014 2903

West Sussex Wheelchair Service

Bognor: 01243 623650
Horsham: 01403 227000, ext. 7160
Worthing: 01273 265850

West Sussex Parent Carer Forum (WSPCF)

Represents parent/carer views to organisations and professional bodies.

Tel: 01903 726188
Email: office@wspcf.org.uk
www.wspcf.org.uk
Local directory

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

ADHD Parent Support Group, Worthing

Support group for parents/carers of children with ADHD.

Tel: 07765 262524 or 07867 786540
Email: twinkletoes71@hotmail.co.uk

Adur Special Needs Project

Out-of-school respite and recreational activities for young people with special needs aged from five to 15 years.

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

Advance Centre

Teaching institute for parents in the methods of the Scotson Technique (TST) which seeks to enhance oxygen supply to the body tissues to help with a range of conditions and disabilities.

Tel: 01342 311137
Email: info@advancecentres.com
www.advancecentres.com

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

Activus, Worthing

Soft play area available for children with special and sensory needs. Facilities include a sensory room, a ball pool, soft shapes, blackboard as well as a television, Nintendo Wii and CD player for slightly older children.

Tel: 01903 231117
Email: worthing@aquaterra.org
http://www.aquaterra.org/centre/activus-worthing/

www.actionfordeafness.org.uk
Albion in the Community (SB)

Runs inclusive sports sessions for young people, as well as disability specific clubs and clubs for wheelchair users.

Tel: 01273 668590, email: disability@albioninthecommunity.org.uk
www.albioninthecommunity.org.uk

Angling4Education (SB)

Delivers fun educational holiday and weekend provision around fishing and the environment for young people with SEND and their families.

Tel: 07795 410812
Email: info@angling4education.co.uk

Ariel Othello’s

Dance, drama, music and singing for children and young people with special needs. Othello Juniors (seven to 19 year olds) and Othello Adults (16+).

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

Arun Counselling Service (Littlehampton)

Confidential counselling service – no one is turned away if they cannot afford to pay. Sessions available daytime, plus some evenings and Saturday mornings.

Tel: 01903 714417
www.arunciounselling.org.uk

Arun Sports Association for the Disabled (ASAD)

Sports club for disabled people aged nine years and over.

Tel: 01243 828695
Email: enquiries@A-S-A-D.org.uk
www.a-s-a-d.org.uk

Ashdown Club (Guild Care) (SB)

Runs weekly and holiday clubs for children aged five to 12 and a youth club for young people aged 12 to 18. Open to children with SEND.

Tel: 01903 528607
Email: ashdown@guildcare.org
www.guildcare.org/ashdown-centre
**Autism Support Crawley**

Support group for parents and carers of children and adults on the autism spectrum or with social communication difficulties. Also has a Facebook group. See website for dates and times of meetings.

Tel: 07596 737741, email: admin@autismsupportcrawley.co.uk
www.autismsupportcrawley.co.uk

**Autism Sussex**

Charity that provides outreach 1-1 support, short breaks and various clubs for children and young people with autism, as well running siblings groups. Also holds workshops, and gives advice and support to families across Sussex.

Tel: 0345 450 0060, email: enquiries@autismsussex.org.uk
www.autismsussex.org.uk

**Belltree Music Therapy Centre**

The Belltree Music Therapy Centre offers a professional music therapy service to people of all ages and abilities in Brighton and Hove and across Sussex.

Tel: 01273 776454
Email: info@belltree.org.uk
www.belltree.org.uk

**Benefits Advisor (WSCC)**

See Essential contacts, page 154

**Bevern Trust**

Enabling people with profound disabilities to live their lives to the full.

Tel: 01273 400752
Email: info@bevernview.org
www.beverntrust.org

**Billingshurst Leisure Centre**

Runs weekly swimming lessons for children, including those with disabilities. Pool has a hoist.

Tel: 01403 787500
www.placesforpeopleleisure.org/centres/billingshurst-leisure-centre

**Blue Badge applications and renewals**

Tel: 01243 777653, email: blue.badges@westsussex.gov.uk
www.westsussex.gov.uk/roads-and-travel/parking
Blue Oasis Clubs

Club nights, autism-friendly film screenings and outreach for young people and adults with learning disabilities and their friends.

Horsham/Crawley tel: 01403 215216
Worthing tel: 01903 221017
Email: blueoasishorsham@gmail.com

Boom Tribe (Horsham)

Weekly Brazilian-inspired percussion workshops for young people with disabilities. Provides young people the opportunity to socialise and perform at events.

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

Branching Out (Westgate Leisure Centre)

Inclusive multi-sports club for children aged 2 to 18 with SEND and their families.

Tel: 01243 785651, email: westgateinfo@everyoneactive.com
www.everyoneactive.com/centre/westgate-leisure-centre

Carers Support West Sussex

Provides free, confidential and impartial information and support to carers in West Sussex. Various support services for carers including the Carers Emergency Alert Card.

Tel: 0300 028 8888
Email: info@carerssupport.org.uk
www.carerssupport.org.uk

Carousel

Carousel works to promote the active involvement of people with a learning disability in the arts, teaching new artistic skills and developing existing talents.

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

Chailey Clinical Services, Sussex community NHS Foundation Trust

Clinical care services for children with complex and multiple physical disabilities. See page 181 for the Rehabilitation Engineering Service.

Tel: 01825 722112
Email: sc-tr.enquirieschcs@nhs.net
www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16344
Chanctonbury Community Playscheme (CCPS) (SB)

A volunteer-led playscheme that runs for four weeks in three West Sussex venues during the summer holidays. Open to children aged five to 19 years with an EHC Plan or Statement of SEN. Parents must fill in a form to apply for a place.

Tel: 07455 131462
Email: ccpsorganiser@gmail.com
www.facebook.com/ccpsplayscheme
www.ccps-sussex.org.uk

Chanctonbury Impulse Leisure Centre

Saturday birth to five years inclusive soft play. Hoist-assisted toilet.

Tel: 01903 746070, email: escrymgeour@impulseleisure.co.uk
www.impulseleisure.co.uk

Charlotte’s Tandems

Free loan of tandems and tag-alongs to people of any age who, due to disability or additional needs, are unable to ride a bike safely on their own. Also loans accessories such as helmets.

www.charlottestandems.co.uk

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 illness from West Sussex. Also runs support groups for siblings cared for by the organisation and those who have been bereaved.

Tel: 01903 871800, email: enquiries@chestnut-tree-house.org.uk
www.chestnut-tree-house.org.uk

Chichester Careline

Various support services for carers including the Carers Emergency Alert Card.

Tel: 01243 778688, email: chichestercareline@chichester.gov.uk
www.chiestercareline.org.uk

Chichester Counselling Service

Affordable counselling for adults and young people aged 14+.

Tel: 01243 789200
office@ccs-counselling.org.uk
www.ccs-counselling.org.uk
Chichester Down Syndrome Support Group

Support group for parents of children and young people with Down syndrome.

Tel: 07500 775596
www.chichesterdownsyndromegroup.co.uk

Chichester Festival Youth Theatre

Youth theatre group held specifically for young people with disabilities. Workshops run every Friday for young people aged 14-18 years.

Tel: 01243 784437
Email: cfyt@cft.org.uk
www.cft.org.uk/take-part/children-young-people

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

Continuing care at home – nursing and care support in the home for children with complex health needs. Health-led short breaks – nursing and care support away from home for children with complex health needs. Referral is via health or social care professionals.

Tel: 01903 708455
Email: heather.mooney@nhs.net
www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16285

Cineworld Cinema

Autism-friendly screenings on the first Sunday of every month.

Tel: 0871 200 2000, email: customer.services@cineworld.co.uk
www.cineworld.co.uk/

Circles Network

A charity working to promote social inclusion and personal empowerment. Services offered include advocacy, transition planning and parent support.

Tel: 01444 236593, email: info.southeast@circlesnetwork.org.uk
www.circlesnetwork.org.uk
Clocktrust, Funtington Time Machine

Inclusive tailored activities in a safe, friendly environment. Also offers post-16 employment opportunities.

Tel: 07823 381118
Email: contact@clocktrust.com
www.clocktrust.com

Coastal Enterprises

Work and training opportunities for adults with learning difficulties.

Tel: 01903 239460, email: martin.fletcher@westsussex.gov.uk
www.vaworthing.org.uk/group/coastal-enterprises

Cobnor Activities Centre

Outdoor activities centre for children and young people with and without special needs.

Tel: 01243 572791
Email: sail@cobnor.com
www.cobnor.com

Community Children’s Nursing Team

Home and community-based nursing for children and young people from birth to 18 years.

Chichester: 01243 793619
Crawley: 01293 600300 ext. 3207
Worthing: 01273 696011 ext. 6200

Compass Card

A discount card for 0 to 25 year olds with significant special educational needs or disabilities in Brighton and Hove or West Sussex.

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

Crawley BMX Track

Inclusive BMX track with specially adapted bikes and part-time instructors.

Tel: 01293 585350, email: sportsdevelopment@crawley.gov.uk
www.crawley.gov.uk

Crossroads Care (SB)

One-to-one short breaks for children with disabilities. Up to four hours per week can be accessed for a maximum of 12 weeks.

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

Counselling, information and support for bereaved people.

Tel: 0300 311 9959, email: westsussexarea@cruse.org.uk
www.cruse.org.uk

Dolphin House

Complementary therapies for children and young people.

Tel: 01273 324790
Email: info@dolphinhouseclinic.com
www.dolphinhouseclinic.com

Dome Cinema


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

Dramatherapy Partnership

Exploration and expression of emotion within a safe and structured setting. For all ages and abilities.

Tel: 07582 239852, email: info@thedramatherapypartnership.co.uk
www.thedramatherapypartnership.co.uk

Drusillas Zoo Park

Accessible zoo located in Alfriston, near Eastbourne. Adult-sized changing bench available in disabled toilet. Also participates in the annual Dream Night event in June, a free evening for severely ill or disabled children.

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

Duke of York’s Cinema (Brighton)

Cinema providing autism-friendly screenings.

Tel: 0871 902 5728 (box office), email: dukeofyorks@picturehouses.co.uk

Early Birth Association

Support group for parents of children at the Trevor Mann Special Care Baby Unit in the Royal Sussex County Hospital, Brighton.

Tel: 01273 696955 and ask for TMBU (ext. 4195)
Email: info@earlybirth.co.uk
http://earlybirth.co.uk
Enable Me
Training in disability awareness for schools and also provides tailored disability awareness training for sports coaches, teaching professionals and businesses.
Tel: 01903 734400, email: office@enablemeproject.org.uk www.enablemeproject.org.uk

Facebook support groups
Some support groups also hold regular meet-ups and events.

ADHD Support Group
Contact Sharon or Sheena
Tel: 07765 262524 or 07867 786540
Email: Twinkletoes71@hotmail.co.uk

Autism by the Sea (Worthing)
Contact Clare Greaves
Email: Greaves.clare@btinternet.com

Horsham Parent SEND Support
For parents of children with social communication needs or autism. For more, join their closed Facebook group.
Contact Jane Cross
Email: Jcross@qe2.co.uk

PATH – Parenting Autism Together in Horsham
Contact Sarah Willis
Tel: 07588 460954
Email: benandsarahwillis@gmail.com

Special Families East Grinstead
Contact Emma Bashford
Tel: 07928 135453, email: admin@specialfamilieseastgrinstead.org.uk
www.specialfamilieseastgrinstead.org.uk

Sussex Autism Support
Offering support and information to parents of children with autism.
Contact Katarina Wilmore
Tel: 07817 250995, email: sussexautismsupport@live.co.uk

Family Support Work
Charity offering support to families in Sussex facing crisis or who need help to overcome multiple complex issues. Services include home visits, support groups, drop-ins, play opportunities for children, and supported family breaks with community workers. Also provides food, clothing and toys where needed.
Tel: 01273 832963, email: admin@familysupportwork.org.uk http://familysupportwork.org
**Ferring Country Centre**


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

**Fibromyalgia Support Worthing & West Sussex**

Support and information for people living with fibromyalgia.

Tel: 07796 653477  
Email: nicholaabond@gmail.com  
www.fmswaws.org

**Finches**

Fully adapted and accessible bungalow offering respite and for children and young people with complex health needs.

Tel: 01444 245117  
Email: sc-tr.finches@nhs.net  

**FindItOut Centres**

Offers information, advice and guidance to young people aged 13 to 25yrs (11 to 12 with a parent/guardian).

Tel: 0330 222 2121  

**Adur**

Lancing Youth Centre, Penhill Road, Lancing, BN15 8HA

Tel: 01903 763639, email: heidi.wyatt@westsussex.gov.uk

**Bognor Regis**

Church Path, Glamis Street, Bognor Regis, PO21 1DB

Tel: 01243 867430, email: lawrence.colwell@westsussex.gov.uk

**Chichester**

New Park Road, Chichester, PO19 7XY

Tel: 01243 538587, email: angela.blackwell@westsussex.gov.uk

**Crawley**

37 Queens Square, Crawley, RH10 1HA

Tel: 01293 843327, email: alex.redford@westsussex.gov.uk
Horsham
Youth Hub@Horsham, Hurst Road, Horsham, RH12 2DN
Tel: 07860 261926, email: alex.redford@westsussex.gov.uk

Littlehampton
82 Wick Street, Littlehampton, BN17 7JS
Tel: 07718 322346, email: lawrence.colwell@westsussex.gov.uk

Mid Sussex
Park Centre, 60 Park Road, Burgess Hill, RH15 8ET
Tel: 01444 243922, email: heidi.wyatt@westsussex.gov.uk

Worthing
The Place, 24 Marine Place, Worthing, BN11 3DN
Tel: 01903 210315, email: heidi.wyatt@westsussex.gov.uk

Flamingoes Club (Crawley)
A swimming club for people with physical disabilities, aged 5+. Meets at K2, Crawley on Tuesday.
Tel: 01293 882148
email kevin@fordo180.freeserve.co.uk

Forest Flyers FC (Horsham)
Football coaching for seven to 18 year olds with disabilities.
Tel: 07715 320631, email: kimberly.roberts@horsham.gov.uk
www.hdsd.org.uk

Gaston Farm
Child-friendly community farm near Slindon. Has disabled parking and is wheelchair accessible.
Tel: 01243 814269
Email: info@gastonfarm.com
www.gastonfarm.com

Gatwick Airport’s Hidden Disability Assistance Programme
For people with autism or hidden disabilities who need extra support and understanding at the airport.

Email:
hidden.disability.at.gatwick@ocs.co.uk
www.gatwickairport.com/at-the-airport/passenger-services/special-assistance/other-assistance/
Golden Lion Children’s Trust

Days out for children with special needs and disabilities and disadvantaged young people.

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

Grace Eyre Foundation

Provides various services designed to help people with learning disabilities access community opportunities including sports, learning and leisure.

Tel: 01273 201900
Email: enquiries@grace-eyre.org
www.grace-eyre.org

Gully’s Days Out
(Albion in the Community)

Opportunities for disabled children and young people to access some of Sussex’s top attractions and leisure facilities.

Tel: 01273 668590,
Email: gullysdayout@albioninthecommunity.org.uk
www.albioninthecommunity.org.uk/disability/gullys-days-out

Gym Joeys

Gymnastics designed to help improve motor and social skills in children aged three to five years, with and without SEND.

Tel: 07799 836341
Email: info@gymjoeys.com
www.gymjoeys.com

Hack Horsham

Runs regular inclusive STEAM (Science, Technology, Engineering, Arts, Maths) workshops and events where children and young people can work on everything from Minecraft to coding and simple circuits

www.facebook.com/hackhorsham
www.hackhorsham.org.uk

Health Visiting Team

www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16308

Healthwatch West Sussex

Independent organisation giving people in West Sussex (especially under-represented groups) an opportunity to have their say about health and care services. Walk-in service at Citizens Advice Bureau,
or contact them via the methods below. (Also see ICAS.)

Tel: 0300 012 0122, email: helpdesk@healthwatchwestsussex.co.uk
www.healthwatchwestsussex.co.uk

Horsham District Sports Development (SB)

The HDSD Reaching Higher Project runs weekly term time after-school short breaks for children over 5 years with SEND. Activities include: dance; percussion; video production; archery; badminton; cricket; inclusive cycling; rebound therapy; table tennis; and wheelchair basketball.

Tel: 01403 215631, email: kimberley.roberts@horsham.gov.uk
www.hdsd.org.uk

Horsham Film Hub (SB)

Inclusive digital production workshops providing the opportunity to learn basic and intermediate production skills in a friendly and fully accessible environment.

Tel: 01403 215631, email: Kimberley.roberts@horsham.gov.uk
Bookings can also be made in person at The Capitol box office or by phoning 01403 750220.

Hyperactive Children’s Support Group

Information and support for families of children who have ADHD or are hyperactive.

Tel: 01243 539966 (Mon – Fri)
Email: hacsg@hacsg.org.uk
www.hacsg.org.uk

Independent Complaints Advocacy Service (ICAS)

Healthwatch’s complaints advocacy service. Any Citizens’ Advice Bureau in West Sussex can refer to ICAS, or they can be contacted directly:

Tel: 0300 303 8536
Email: icas@westsussexcab.org.uk

Independent Lives

Information, care and support services designed to enable people with care needs to be independent. Direct payments/personal budget support and payroll service.

Tel: 0845 601 2399 or 01903 219482
Email: feedback@independentlives.org
www.independentlives.org
K2 Leisure Centre, Crawley
(Freedom Leisure)

Recreational play, sports activities and swimming lessons for anyone of five years and over with special needs/disabilities. Also holds family fun days.

Tel: 01293 585300, email: k2enquiries@freedom-leisure.co.uk
www.freedom-leisure.co.uk

Kamelia Kids

Inclusive day nursery for children aged up to eight years old in Worthing.

Tel: 01903 504077
www.kameliakids.org.uk

Kangaroos (SB)

After-school clubs, weekend and holiday playschemes for children (aged 6+) and young adults with SEND. Activities are tailored to ages and abilities. Main clubs: PALS, STARS, BreakAway, No Limits. After-school and evening clubs: AllSports, Champions, TeenScene, Youth Club, Social Club.

Tel: 01444 459108
Email: info@kangaroos.org.uk
www.kangaroos.org.uk

KIDS (SB)

Short breaks to help disabled children aged 6 to 18 years in the Chichester area to go out into the community and access groups.

Tel: 01329 312312
www.kids.org.uk/chichester-short-breaks

Lancing Manor Impulse Leisure Centre

Saturday birth to five years inclusive soft play sessions. Hoist-assisted toilet available.

Tel: 01903 524624, email: escrymgeour@impulseleisure.co.uk
www.impulseleisure.co.uk

Learning Assessment and Neurocare Centre

Assessment and management of children with complex neurodevelopmental difficulties.

Tel: 01403 240002
Email: info@lanc.uk.com
www.lanc.uk.com
Libraries

When applying for a Compass Card (see page 167), you can opt for it to double up as their West Sussex library card, which gives them free access to a range of books and online resources, as well as fun activities and events.

Angmering: 01903 772682
Arundel: 01903 883188

Billingshurst: 01403 783145
Bognor Regis: 01243 382470
Broadfield: 01293 543298
Broadwater: 01903 233244
Burgess Hill: 01444 255452

Chichester: 01243 777351
Crawley: 01293 651751

Durrington: 01903 260439

East Grinstead: 01342 332900
East Preston: 01903 786118

Ferring: 01903 241811
Findon Valley: 01903 872213

Goring: 01903 244300

Hassocks: 01273 842779
Haywards Heath: 01444 255444
Henfield: 01273 493587
Horsham: 01403 224353
Hurstpierpoint: 01273 832609

Lancing: 01903 839056
Littlehampton: 01903 716450

Midhurst: 01730 716671
Petworth: 01798 342274
Pulborough: 01798 872891

Rustington: 01903 785857

Selsey: 01243 602096
Shoreham-by-Sea: 01273 467966
Southbourne: 01243 375924
Southwater: 01403 734660
Southwick: 01273 592150
Steyning: 01903 270330
Storrington: 01903 839050

Willowhale: 01243 265712
Witterings: 01243 673484
Worthing: 01903 704809

www.westsussex.gov.uk/find-my-nearest/library

Lizzie’s Craft Club

Craft club for children aged four to 11 years in a custom-built, wheelchair accessible art studio.

Tel: 07900 631527
Email: lizzie@lizziebaily.com
www.lizziebaily.com
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.

Chichester & Arun – Stonepillow
Restore, Unit 3, 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
Your youngest child must be of school age to access this service.
Riverside House, Stephenson Way
Three Bridges, Crawley, RH10 1TN
Tel: 01293 447700, email: senioradvice@crawleyopenhouse.co.uk
www.crawleyopenhouse.co.uk/advice-and-lan

Horsham district – Horsham Matters
Address: Micah House, Blatchford Road, Horsham, RH13 5QR
Tel: 01403 211833, email: support@horsham-matters.org.uk
http://horsham-matters.org.uk/needhelp/

Littlehampton – Worthing Churches Homeless Projects
Address: Littlehampton United Church, 1 High Street, BN17 5RG
Tel: 07702 872377, email: lanlittlehampton@wchp.org.uk
www.wchp.org.uk/what-we-do/littlehampton-breakfast-club/

Worthing and Shoreham – Worthing Churches Homeless Projects
Address: St Clare’s Day Centre, 6-8 Marine Place, Worthing, BN11 3DN
Tel: 01903 680748
Email: lan@wchp.org.uk
www.wchp.org.uk/what-we-do/st-claires-day-centre

UK Foodbank Network (The Trussell Trust)
Phone to be put in touch with your nearest foodbank, or use the search box on the website.
Tel: 01722 580180
Email: enquiries@trusselltrust.org
www.trusselltrust.org

Lodge Hill Centre
Outdoor education centre, activities and conference facilities. Fully accessible lodge.
Tel: 01798 831411
www.lodgehill.org.uk
Look Sussex

Provides support to the families of children with a visual impairment in East and West Sussex.

Tel: 01273 677731
Email: Tara.dutton@btinternet.com
www.looksussex.org.uk

M8s Youth Club (West Sussex Young People’s Service)

Weekly youth club and support group for young people with special needs aged 13 to 25. Horsham group meets at Horsham Youth Centre. Bognor Regis group meets at the Phoenix Centre. Term-time only.

Horsham – email:
sally.sikora@westsussex.gov.uk
Bognor Regis – email:
Maria.Parton@westsussex.gov.uk

Mastersport – Angling

Inclusive angling sessions for young children. Sports and activities for young people and adults with disabilities.

Tel: 07919 155174 07493 611384 or 01424 846951, email:
inforoy.masters@mastersport.org.uk

Mid Sussex Marlins

Swimming club that has two groups for children and adults with special needs and disabilities. Dolphins in Burgess Hill and Starfish at Haywards Heath.

General enquiries:
info@midsussexmarlins.org
Email Pauline at:
dolphins@midsussexmarlins.org
Email Carolyn at:
starfish@midsussexmarlins.org
www.midsussexmarlins.org/disabilities

Mid Sussex Mencap

Provides support, social activities and funding to people with learning disabilities.

Tel: 01444 471431, email:
chair@midsussexmencap.org.uk
www.midsussexmencap.org.uk

Mid Sussex Support Group for Parents of Autistic Children

Informal support group which meets at The Yews Centre in Haywards Heath.

Tel: (The Yews Centre reception)
01444 412367
www.theyewscentre.org.uk/about.html
**Mohair Centre**

A working farm offering a holiday playscheme, after-school club and nursery. able to include children aged up to 11 years with additional needs.

Tel: 01825 872457, email: mohairchildcare@hotmail.co.uk
www.mohaircentre.co.uk

**Money Advice Plus**

Counselling, advice and support for people in Sussex who are having trouble managing their finances.

General tel: 01273 664000
Advice Line (debt and benefits) tel: 0800 988 7037, email: info@moneyadviceplus.org.uk
www.moneyadviceplus.org.uk

**Moving Barriers Club**

Sporting activities for disabled people aged six to 25 living in or near Crawley.

Tel: 01293 585350
Email: matt.laird@crawley.gov.uk
www.freedom-leisure.co.uk/centres/k2-crawley/disability-sport-at-k2-crawley

**Moving Forward**

(Barnardo’s, Crawley)

Life skills youth group for young people with learning difficulties or disabilities aged 12 to 18.

Tel: 01293 610692, email: moving.forward@barnardos.org.uk

**MXT Swimming School**

Has swim teachers experienced in working with children with autism, muscular dystrophy, ADHD, dysphasia, dyspraxia and cerebral palsy.

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

**My Care Passport**

Helps parent carers to share important information about their child with hospital staff during a visit or a stay in hospital, so they can understand their needs. You can find a blank template to fill out at:

National Autistic Society (NAS) Horsham Club  

Club for five to 18 year olds with autism held at Lavinia House. Fun activities in a safe, structured and autism-friendly environment.

Tel: 01483 521743, email: SEResourceCentres@nas.org.uk

Oak Grove College/Worthing Leisure Centre  

Inclusive holiday and after-school clubs. Activities include: cooking, crafts, fencing, film-making, music, photography, swimming, tennis, and trampolining.

Tel: Claire Moyle 07762 013949, email: Cmoyle@oakgrovecollege.org.uk http://oakgrovecollege.org.uk/our-college-2/subjects/extended-college-activities/

Offington Counselling Service (Worthing)  

Confidential counselling service for people on a limited budget 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. Ducks, rabbits, sensory play hut. Gifts, activity classes, home-made food. Wheelchair accessible. Run from home by a family whose children have special needs. Friendly environment.

40 Links Avenue  
Felpham  
PO22 7BX  
Tel: 07496 076846  
http://olive-tree-cottage.org/

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
Outreach 3 Way

Provides day services, sheltered employment and housing for people with learning disabilities and autism.

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

Parents and Carers Support Organisation (PACSO) (SB)

Runs a number of after-school clubs, weekend activities, and holiday playschemes for children with SEND aged between birth and 25 years.

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

Parents for Autism (Worthing)

Support group for parents, relatives and carers of children and young people with autism. Meets at the Maybridge Centre, Worthing.

Tel: 07876 196944, email: lindsey@parentsforautism.org.uk
www.parentsforautism.org.uk

Patient Advice and Liaison Service (PALS)

Information and advice service (including complaints) for NHS patients.

Worthing & Southlands
Tel: 01903 285032, email: PALSWorthing@wsht.nhs.uk

St Richard’s, Chichester
Tel: 01243 831822, email: PALSChichester@wsht.nhs.uk
www.westernsussexhospitals.nhs.uk/services/patient-advice-and-liaison-service-pals-complaints

Pavilions in the Park
(Horsham Leisure Centre)

Runs swimming lessons for children aged between five and 18 years.

Tel: 01403 219200

Percussion and DJ/Music Production (SB)

Fully inclusive and accessible percussion and DJ/Music Production courses. Courses are for all abilities and run in Horsham every Friday over a ten-week period (term-time only).
Phoenix Centre Sensory Room

A fully equipped sensory room for children and adults with special needs.

Tel: 01243 840075, email: YPS.admin@westsussex.gov.uk
www.phoenixcentrebognorregis.uknic.biz

Puzzle Pieces (Bognor)

Parent-led support group for parents with children 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

Provides emotional and practical support to families of children with life-threatening or terminal illnesses.

Tel: 01372 363438, email: enquiries@rainbowtrust.org.uk
www.rainbowtrust.org.uk

Reaching Families

Information, training and support to parents and families of children with SEND in West Sussex.

Tel: 01903 502649, email: admin@reachingfamilies.org.uk
www.reachingfamilies.org.uk

Ready and Able Sports Club (Horsham)

Sports and social club for people with disabilities (16 and over) and their families.

Tel: 01403 215637
Email: paul.taylor@horsham.gov.uk

Rehabilitation Engineering Service (Chailey Clinical Services)

Provides 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

Counselling, mediation and therapy for couples and families.

Chichester tel: 01243 788935, email: reception.chichester@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 reception@brightonrelate.org.uk

Horsham tel: 01403 266454, email: reception.crawley@relatesussex.org

Worthing tel: 01903 202 512, email: worthing@brightonrelate.org.uk

Rhythmix Music Workshops

Music workshops available to children and young people with disabilities aged five to 18.

Tel: 0870 141 7484
Email: info@rhythmixmusic.org.uk
www.rhythmixmusic.org.uk

Sensory Support Team

Provision of services to children and young people aged 0 to 19 with hearing or sight impairments.

Tel: 01903 270430, email: sensory.support@westsussex.gov.uk
www.westsussex.gov.uk/education-children-and-families (click on ‘SEND’, then ‘support for children with visual and hearing impairment’.)

Shine Theatre Trust

Inclusive theatre group for children and young people.

Tel: 01273 833196
Email: office@shinetheatretrust.org
www.shinetheatretrust.org

Short Breaks for Disabled Children

Holiday clubs, after-school clubs, buddy schemes and short breaks at home or in the community for children and young people up to the age of 18.

Tel: 0330 222 2562, email: short.break.team@westsussex.gov.uk
www.westsussex.gov.uk/education-children-and-families (click on ‘SEND’, then ‘Short Breaks’.)
Signposts

Information, advice, training and activities for adults and children 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, online networking and volunteering opportunities for single parents in Brighton and Sussex.

Tel: 07948 971559
Email: SPIN@live.co.uk
www.spinbrighton.org

Smile Support and Care

Provides one-to-one care for disabled children and young adults in West Sussex and Hampshire, and respite care.

Tel: 02380 616215, email: sussex.enquiries@smilesupport.org.uk
www.smilesupport.org.uk

SNAPS

Drop-in support group for parents and carers of children with SEND aged from birth to 16. held at St Matthew’s church, Worthing.

Tel: 01903 207024
www.stmatthewsworthing.co.uk

Southern Area Disability Sports Group

Sporting activities for children and young people with disabilities.

Tel: 01903 778328, email: agroves@angmeringschool.co.uk

Southwick Impulse Leisure Centre

Family Fun Days for children with special needs and disabilities and their families. Saturday birth to five years inclusive soft play. Extra Time holiday clubs.

Tel: 01273 238111, email: escryanmeour@impulseleisure.co.uk
www.impulseleisure.co.uk

Special Needs And Parents (SNAP)

A weekly play and support group for children with additional needs and their families based in Horsham.

Tel: 01403 224430, email: office@horshamnursery.co.uk
www.horshamnursery.w-sussex.sch.uk
The Springboard Project (SB)

Inclusive play, recreation centre and other support for children and young people with special needs and their families. Also runs short breaks clubs: 6 – 12 (Crawley, Horsham and Worthing) and 12 – 18 and 18 – 25 (Crawley and Horsham).

Horsham tel: 01403 218888 / 01403 257699 (short breaks)
Crawley tel: 01293 531963 / 01293 542821 (short breaks)
Email: info@springboardproject.com www.springboardproject.com

Stay Up Late

A charity providing support to people with learning disabilities aged 18+, including buddies to accompany young people to gigs.

Tel: 01273 468168
Email: info@stayuplate.org www.stayuplate.org.

Steyning Leisure Centre

Swimming lessons and float sessions for disabled children aged five to 18 years.

Tel: 01903 879666
www.placesforpeopleleisure.org/centres/steyning-leisure-centre

Sunbeam Swim Club

Swimming group for disabled children and adults, held at Pavilions in the Park, Horsham.

Tel: 01403 253200
www.hdsd.org.uk/Inclusive-Activities/disabilities/sports-clubs

Sussex Association for Spina Bifida and Hydrocephalus (SASBAH)

Advice, support and residential breaks for children and young people with spina bifida and/or hydrocephalus and their families. Also runs a buddy scheme open to people with any disability.

SASBAH Advisor service
tel: 01903 230782
Email: zoe@sasbah.org.uk
Other enquiries, tel: 01825 873045
Email: lisa@sasbah.org.uk www.sasbah.org.uk

Sussex Cricket Club

Holds weekly inclusive cricket sessions and holiday camps in Chichester, Horsham and Worthing.

Tel: 0844 264 0203, email: colin.bowley@sussexcricket.co.uk www.sussexcricket.co.uk/current-courses
Sussex Deaf Association

Information, advice, training and community support to people who have hearing impairments.

Tel/Minicom: 01273 671899
SMS Text: 07958 655127
Email: info@sussexdeaf.com
www.sussexdeaf.com

Sussex Otters Swimming Club

Volunteer-supported swimming club for all ages of people with disabilities. Meets at Westgate Leisure Centre, Chichester.

Tel: 01243 539181 or 01243 582545
Email: administrator@sussexotters.org.uk
www.sussexotters.org.uk

Sussex Snowdrop Trust

Support and care at home for children with life-threatening or life-limiting conditions.

Admin office tel: 01243 572433
Nurses station: 01243 793619, email: info@thesussexsnowdroptrust.com
www.thesussexsnowdroptrust.com

Sussex Sonics (Brighton)

Wheelchair basketball club for people with disabilities.

Tel: 01273 307505

Sussex Squids

Competitive swim squad for anyone over the age of eight with SEND. Meets at Freedom Leisure, Littlehampton.

Tel: 07780 540104 (Bob Jones)
Tel: 07952 138244 (Grace)
Email: bob.jones@gardnerandscardifield.co.uk/Tansley

Sussex Wasps (Brighton)

Disabled sports club for people of all ages and abilities. Includes: javelin, discus, bowls, archery, wheelchair basketball, tennis, table tennis and track events.

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

Time Aside

Sensory art workshops providing creative fun for the whole family using a rich array of materials.

Tel: 07792 903236 (Sueloo Brown)
Email: sueloo@timeaside.com
www.timeaside.com
Umbrellas Parent Support Groups

Support for parents/carers of children with special needs and disabilities who attend mainstream schools. Run by Reaching Families.

Billingshurst/Hayward Heath groups
Tel: 07470 005734 (Michelle Creed)
Email: michele@reachingfamilies.org.uk

Littlehampton/Worthing groups
Tel: 07704 037664 (Rosemary Hudson)
Email: rosemary@reachingfamilies.org.uk

Wadurs Pool Impulse Leisure Centre

Swimming lessons for children with physical disabilities in Shoreham.

Tel: 01273 238000, email: escrymgeour@impulseleisure.co.uk
www.impulseleisure.co.uk

Wellspring

Provides information, services and resources to children and young people with disabilities and their families.

Tel: 07742 408868, email: lizzie@wellspringwestsussex.org.uk
www.wellspringwestsussex.org.uk

Westgate Leisure Centre (Chichester)

Various sports and leisure activities including inclusive swimming and trampolining for children aged five and over.

Tel: 01243 785651, email: westgateinfo@everyoneactive.com
www.everyoneactive.com/centre/westgate-leisure-centre/

West Sussex Parent Carer Forum (WSPCF)

For parent carers of children and young people with SEND aged up to 25. Represents parent/carer views to organisations and professional bodies.

Tel: 01903 726188
Email: office@wspcf.org.uk
www.wspcf.org.uk

West Worthing Tennis Club

Term-time tennis lessons for children and young people with SEND aged eight+.

Tel: Claire Moyle 07762 013949, email: Cmoyle@oakgrovecollege.org.uk
www.wwc.org.uk
**Wheels for Wellbeing (Crawley)**

Specialist cycle track with adapted cycles for wheelchair users and people with disabilities. Offers coaching sessions, group rides and group events.

Tel: 01293 585355, email: WheelsForWellbeing@crawley.gov.uk
www.crawley.gov.uk/wfw

**Whoopsadaisy**

Courses in conductive education for children with cerebral palsy and physical developmental delays and their parents.

Tel: 01273 554178 or 07588 555761
Email: info@whoopsadaisy.org
www.whoopsadaisy.org

**Windmills Opportunity Playgroup**

Inclusive playgroup for children with and without additional needs.

Tel: 01444 220378, email: admin@windmillsplaygroup.co.uk
www.windmillsplaygroup.co.uk

**Winston’s Wish**

National charity with an active branch in West Sussex providing support to bereaved children.

Tel: 01403 211030, email: info@winstonswish.org.uk
www.winstonswish.org.uk

**Worth Services**

Independent service supporting people affected by domestic abuse.

Tel: 0330 222 8181
01903 205111 ext. 84395
or call/text: 07834 968539
www.worthservices.org

**Worthing and District Scope**

Various activities and other services for children, young people and adults with additional physical needs.

Tel: 01903 522366, email: admin@worthingscope.org.uk
www.worthingscope.org.uk

**Worthing Kids and Dapper Snapper**

Support group for children with SEND and their families. Organises group activities and outings.

Tel: 07570 768893
Email: info@wkds.org
www.wkds.org
Worthing Lego Club

Run for children and young people with additional needs and their families. Held on the last Saturday of the month at St John’s Church Hall, Worthing.

Tel: 07538 375936
www.facebook.com/worthing.lego.club

Worthing Leisure Centre (South Downs Leisure)

Various sports and leisure activities for children, and young people with disabilities, including trampolining and Special Olympics athletics for people aged 8+ who have SEND.

Trampolining, tel: 01903 502237
Wheelchair racing and Special Olympics, tel: Claire Moyle 07762 013949, email: Cmoyle@oakgrovecollege.org.uk
www.southdownsleisure.co.uk

Worthing Mencap

Local branch of the national charity. Runs a café, information centre, charity shop, and various clubs, activities and services for people with learning disabilities, their families and carers.

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

YMCA East Surrey

Runs Saturday term-time clubs and holiday schemes – Yippee for five to 11 year olds and Yip4Youth for 12 to 18 year olds with SEND in West Sussex.

Tel: 01737 222859, email: sovereign@ymcaeastsurrey.org.uk
www.ymcaeastsurrey.org.uk

Young Carers

Service run by West Sussex County Council to support young carers.

Tel: 01903 270300, email: youngcarers@westsussex.gov.uk

Your Space

Information and advice for young people aged 11 to 25. Includes information on jobs, education, bullying, health, leisure, support for SEND and much more.
Tel: 07868 324322, email: editor@yourspacewestsussex.co.uk
www.westsussex.gov.uk/education-children-and-families/your-space

Your Space, Your Time
(Shoreham-by-Sea)

Activities for children and young people aged five to 23 with motor, sensory, behavioural or learning difficulties. Runs on two weekends each month, and during school holidays.

Tel: 01273 465616, email: info@yourspaceyourtime.co.uk
www.yourspaceyourtime.co.uk
**Ability Net**

Helps children and adults with disabilities to use computers and access the internet.

Tel: 0800 269 545 or 01926 312847
Email: enquiries@abilitynet.org.uk
www.abilitynet.org.uk

**ABLEize**

Comprehensive online directory of disability and health care information and products, run by people with disabilities.

www.ableize.com

**Action against Medical Accidents (AvMA)**

Provides independent advice and support to people affected by medical accidents and works in partnership with healthcare bodies to improve patient safety.

Tel: 0845 123 2352
www.avma.org.uk

**Action for All Speech Impaired Children (AFASIC)**

Information, advice and training for parents of children with speech, language and communication needs.

Tel: 0300 666 9410
www.afasic.org.uk

**Action for ME**

Online information and resources for people who have Myalgic Encephalomyelitis (ME).

Tel: 0117 927 9551
Email: questions@actionforme.org.uk
www.actionforme.org.uk

**Action for Sick Children**

Campaigns on all aspects of children’s healthcare.

Tel: 0800 074 4519 (helpline), email: enquiries@actionforsickchildren.org.uk
www.actionforsickchildren.org.uk

**Action on Hearing Loss**

Information and advice for people with hearing loss and tinnitus.

Tel: 0808 808 0123
Textphone: 0808 808 9000, email: informationline@hearingloss.org.uk
www.actiononhearingloss.org.uk

**Aidis Trust**

Information, advice, training and technical support to enable disabled people to better use computers and assistive technology.

Tel: 0808 800 0009
www.aidis.org
Ambitious about Autism

Training and campaigning for improved opportunities for children and young people with autism. Specialist education through TreeHouse School and Ambitious College.

Tel: 020 8815 5444, email: info@ambitiousaboutautism.org.uk
www.ambitiousaboutautism.org.uk

Arthritis Care

Information, training, networking and campaigning on behalf of people with arthritis.

Tel: 0808 800 4050
Email: info@arthritiscare.org.uk
www.arthritiscare.org.uk

Artsline

A disability access website, providing searchable information on over 1,000 arts venues across London.

www.artsline.org.uk

Asian People’s Disability Alliance (APDA)

Information, advice, day care, home respite, sports and arts for Asian people with disabilities.

Tel: 020 8459 1030
Email: info@apda.org.uk
www.apda.org.uk

Association for Real Change (ARC)

Information, advice, 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)

Provides information, advice, training and therapy to children and adults with communication, eating, drinking or swallowing difficulties.

Tel: 01684 576795
Email: admin@arcos.org.uk
www.arcos.org.uk

Asthma UK

Organisation offering support to people with asthma. Helpline is manned by asthma nurses who can advise people about medications and their asthma care plan.

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 living with ADHD/ADD and their carers/families.

Tel: 020 8952 2800
Email: info@addiss.co.uk
www.addiss.co.uk

Barnardo’s

Charity that offers support to young carers and siblings of children with a disability or illness.

www.barnardos.org.uk/what_we_do/our_work/young_carers.htm

Birth Trauma Association

Information and support for women and families who have had a traumatic birth experience.

www.birthtraumaassociation.org.uk
Facebook: www.facebook.com/groups/TheBTA

Bladder and Bowel UK

Offers advice and information on all bladder and bowel issues, with a dedicated section for children and young people, including those with SEND.

Tel: 0161 6078219
Email: bladderandboweluk@disabledliving.co.uk
www.bladderandboweluk.co.uk

Bobath Centre

Specialist therapy for children and adults with cerebral palsy and similar neurological conditions. Therapy designed to enhance personal independence.

Tel: 020 8444 3355
Email: enquiries@bobath.org.uk
www.bobath.org.uk

Brain and Spine Foundation

Information, advice and training for people affected by neurological conditions.

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 Deaf Association (England)
Organisation that campaigns for equality for deaf people.
Tel: 020 7697 4140
Email: bda@bda.org.uk
www.bda.org.uk

British Dyslexia Association
Information and advice for people with dyslexia. Includes information on early help and how to support your child’s learning.
Tel: 0333 405 4567
Email: helpline@bdadyslexia.org.uk
www.bdadyslexia.org.uk

British Institute for Brain Injured Children (BIBIC)
Works with children aged 6 months and up with brain injuries and other conditions including autism, cerebral palsy, Down syndrome, development delay and children without a diagnosis.
Tel: 01458 253344
Email: info@bibic.org.uk
www.bibic.org.uk

British Kidney Patient Association
Information, advice and grants for people in the UK with kidney disease.
Tel: 01420 541424
Email: info@britishkidney-pa.co.uk
www.britishkidney-pa.co.uk

Brittle Bone Society
Information, advice and grant funding for people with brittle bone disease.
Tel: 01382 204446
Email: bbs@brittlebone.org
www.brittlebone.org

Brook Advisory Centre
Information, advice and support on sexual health for young people aged under 25.
www.brook.org.uk/our-services/ask-brook-a-question-24-7

Care Quality Commission
Independent agency regulating health and social care in England.
Tel: 0300 061 6161
Email: enquiries@cqc.org.uk
www.cqc.org.uk
Carers Trust

Information, advice, support and a network of local services for carers.

Tel: 0300 772 9600
General enquiries, email: info@carers.org
Support for carers, email: support@carers.org
www.carers.org

Challenging Behaviour Foundation

Information, support, advice and workshops for families of people with severe learning disabilities and challenging behaviour.

Tel: 0300 666 0126 (family support service)
Email: support@thecbf.org.uk
www.challengingbehaviour.org.uk

Carers UK

Advice and support for carers, including a helpline, fact sheets, online forum and information about Carer’s Allowance.

Tel: 0808 808 7777
Email: info@carersuk.org
www.carersuk.org

Changing Faces

Support and resources for people who have any condition or injury that affects their appearance.

Tel: 0300 012 0275, email: support@changingfaces.org.uk
www.changingfaces.org.uk

Cerebra

Information and advice for families of children with neurological conditions, including autism and learning disabilities. Also runs a service for sleep issues and a lending library offering books and sensory equipment.

Tel: 01267 244200
Email: enquiries@cerebra.org.uk
w3.cerebra.org.uk

Child Bereavement UK

Supports families when a child of any age dies or is dying or when a child is facing bereavement.

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 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, no matter how long ago.

Tel: 0800 282 986 (from a landline) or 0800 800 6019 (from a mobile)
Email: contact@childdeathhelpline.org
www.childdeathhelpline.org.uk

**Child Maintenance Service (CMS)**

Government agency that seeks to ensure parents who live apart from their children contribute financially to their upkeep.

Tel: 0345 266 8792
https://childmaintenanceservice.direct.gov.uk/public/

**Children’s Heart Association**

Supports families of children with heart disorders.

Tel: 01706 221988
Email: information@heartchild.info
www.heartchild.info

**Children’s Heart Federation**

Information, advice and small grants to families of children with heart conditions.

Tel: 0808 808 5000
Email: info@chfed.org.uk
www.chfed.org.uk

**Cleft Lip and Palate Association (CLAPA)**

For families of children with a cleft lip and/or palate, includes a specialist feeding service, targeted information, local support and residential weekends for nine to 15 year olds.

Tel: 020 7833 4883
Email: info@clapa.com
www.clapa.com

**Climb**

Information for children, young people and families affected by inherited metabolic disorders.

Tel: 0845 241 2173
Email: contact@climb.org.uk
www.climb.org.uk
The Compassionate Friends

A parent-led group that offers support and care to other parents, grandparents and siblings who have suffered the death of a child.

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.

Tel: 01268 284834 or 07949 530509
Email: bigpaulh@blueyonder.co.uk
www.cftd.co.uk

Contact a Family (CAF)

National charity for families of children with special needs, disabilities or medical conditions. Provides information, advice and support; brings families together so they can support each other; campaigns to improve families’ circumstances and for their right to be included and equal in society.

Tel: 0808 808 3555 (free helpline)
Email: helpline@cafamily.org.uk
www.cafamily.org.uk

Coram Children’s Legal Centre

Provides legal advice, information and representation for children and young people and their families.

Family/child law, tel: 0300 330 5480
Education law, tel: 0300 330 5485
General information:
www.childrenslegalcentre.com
Legal advice:
www.childlawadvice.org.uk

Council for Disabled Children

Umbrella organisation that campaigns on behalf of the disabled children’s sector. Online resource library.

Tel: 020 7843 1900
Email: cdc@ncb.org.uk
www.councilfordisabledchildren.org.uk

Cry-Sis

Information and advice to families who have demanding babies, or issues with excessive crying or sleep.

Tel: 0845 122 8669
Email: info@cry-sis.org.uk
www.cry-sis.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

Dame Vera Lynn Children’s Charity

Provides a services for under fives with cerebral palsy and other motor learning difficulties, including an early intervention service; physical therapy sessions; outreach support in the home; Saturday and holiday clubs; a parent support network; and access to assistive technology.

Tel: 01444 473274
Email: info@dvlcc.org.uk
https://dvlcc.org.uk/

Diabetes UK

Information, advice and support for people living with diabetes.

Tel: 0345 123 2399
Email: info@diabetes.org.uk
www.diabetes.org.uk

Disability Equipment Service
(formerly AskDES)

Second-hand disability equipment service.

Tel: 07845 041678
www.disabilityequipmentservice.co.uk

Disability Law Service

Legal advice and representation for disabled people and their carers.

Tel: 020 7791 9800
Email: advice@dls.org.uk
www.dls.org.uk

Disability Rights UK

Promotes equal participation for all. Can offer advice on independent living, education and careers. Also has helplines – see website for more.

Tel: 020 7250 8181, email: enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org

Disabled Living Foundation

Provides information, advice and training on equipment for independent living.

Tel: 0300 999 0004
Email: info@dlf.org.uk
www.dlf.org.uk
Down’s Heart Group

Offers support and information relating to heart conditions associated with Down syndrome.

Tel: 0300 102 1644
Email: info@dhg.org.uk
www.dhg.org.uk

Down’s Syndrome Association

Information, advice, and support for carers of people with Down syndrome.

Tel: 0333 121 2300
Email: info@downs-syndrome.org.uk
www.downs-syndrome.org.uk

Dyspraxia Foundation

Information, advice for people with dyspraxia, also known as Development Coordination Disorder (DCD).

Tel: 01462 454986, email: info@dyspraxiafoundation.org.uk
www.dyspraxiafoundation.org.uk

English Federation of Disability Sport

Works to make sure disabled people can lead active lives. Supports sports organisations so they can be as inclusive as possible.

Tel: 01509 227750
www.efds.co.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

Advises and assists individuals on issues relating to equality and human rights, such as disability rights and discrimination. Has online resources such as template letters.

Tel: 0808 800 0082
Text: 0808 800 0084
www.equalityadvisoryservice.com

ERIC – The Children’s Bowel and Bladder Charity

Information on bowel and bladder health for children and teenagers. Includes a helpline service for parents, downloadable resources and an online shop selling continence products.
Tel: 0845 370 8008
Email: helpline@eric.org.uk
www.eric.org.uk

**Evelina London Children’s Healthcare**

Part of Guy’s and St Thomas’ NHS Trust, this is a specialist hospital offering treatment to children and young people from across the South East.

Tel: 020 7188 7188
www.evelinalondon.nhs.uk

**Family Lives**

Information, advice and support to parents and carers on any aspect of family life.

Tel: 0808 800 2222, email: familysupport@familylives.org.uk
www.familylives.org.uk

**Family Rights Group**

Advises, advocates and campaigns for families who need, or are involved with, local authority children’s services.

Tel: 0808 801 0366
www.frg.org.uk

**Fledglings**

Finds and sells products that improve the lives of disabled children and their families.

Tel: 01799 541807
Email: enquiries@fledglings.org.uk
www.fledglings.org.uk

**Foundation for People with Learning Disabilities**

Wide range of services providing information, training, day care, support and campaigning on behalf of people with learning disabilities.

Tel: 020 7803 1100
Email: fpld@fpld.org.uk
www.mentalhealth.org.uk/learning-disabilities

**Fragile X Society**

Offers information, advice and peer support to families of children with Fragile X Syndrome. Has a newsletter, helpline service and online resources.

Tel: 01371 875100
Email: info@fragilex.org.uk
www.fragilex.org.uk
Gingerbread
Organisation supporting single parents. Offers online advice and information as well as a forum and local groups and meet ups.
Tel: 0808 802 0925
www.gingerbread.org.uk

Girlguiding UK
National umbrella organisation for girl guides throughout the UK.
Tel: 020 7834 6242
www.girlguiding.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.
Helpline: 0300 123 7015
advice@grandparentsplus.org.uk
www.grandparentsplus.org.uk/disability

Great Ormond Street Hospital (GOSH)
A leading specialist children’s hospital based in London. Children and young people are mostly referred to GOSH by their local paediatricians.
Tel: 020 7405 9200
www.gosh.nhs.uk

Guide Dogs
Information and advice for people with visual impairments – has various specialised services for children and young people.
Tel: 0800 781 1444
Email: guidedogs@guidedogs.org.uk
www.guidedogs.org.uk

Headway
Support, information and services to people affected by brain injuries, as well as their families and carers.
Tel: 0808 800 2244
Email: helpline@headway.org.uk
www.headway.org.uk

Heartline
Supports children with heart disorders and their families. Has
an online forum, a handbook for parents, weekend activities for children and offers peer-to-peer support.

Email: intouch@heartline.org.uk
www.heartline.org.uk

HemiHelp

Information, advice, training, local groups and advice on daily living for families of children with hemiplegia.

Tel: 0345 123 2372
Email: helpline@hemihelp.org.uk
www.hemihelp.org.uk

Henry Spink Foundation

Information and resources on a wide range of conventional and complementary therapies available for SEND.

www.henryspink.org

ICAN

Information services providing help and advice to parents about speech, language and communication as well as training for practitioners.

Tel: 020 7843 2544 (free call back service)

Email: help@ican.org.uk
www.ican.org.uk

JABS

Support group for parents of children who have had a serious health problem following vaccination.

Tel: 01942 713565
www.jabs.org.uk

Letterbox Library

A book club that specialises in multicultural books and has a selection of books featuring children with SEND.

Tel: 020 8534 7502
Email: info@letterboxlibrary.com
www.letterboxlibrary.com

Listening Books

An UK charity that supplies an audiobook service for children and adults who find it difficult to read due to illness or a disability. Books can be accessed via downloads, streaming or an MP3 CD.

Phone: 020 7407 9417
Email: info@listening-books.org.uk
www.listening-books.org.uk
LittleBlueCup

Volunteers post searches to help families of disabled children to replace discontinued cups, toys and other small essentials that they cannot do without.

Tel: 07470357701
Email: marc@littlebluecup.org
www.facebook.com/LittleBlueCup

Local Government Ombudsman

Investigates complaints about local authorities and other organisations providing public services.

Tel: 0300 061 0614
Or text ‘call back’ to: 07624 811595
www.lgo.org.uk

The Makaton Charity

Resources, information and training workshops on the Makaton communication system for families and carers.

Tel: 01276 606760
Email: info@makaton.org
www.makaton.org

Mencap

Wide ranging services for people with learning disabilities and their families and carers, including family support, wills and trusts, and benefits advice.

Tel: 0808 808 1111
Email: helpline@mencap.org.uk
www.mencap.org.uk

MERU

Designs and makes custom-built equipment for children and young people with disabilities.

Tel: 01372 725203
Email: info@meru.org.uk
www.meru.org.uk

Mind

Provides advice and support to empower people with mental health issues.

Mind Infoline, tel: 0300 123 3393
Text: 86463
Email: info@mind.org.uk
www.mind.org.uk

Motability

National scheme enabling people to exchange the Higher Rate Mobility component of DLA or the Enhanced Rate of Mobility Component of PIP for a car, powered wheelchair, or scooter.
Tel: 0300 456 4566
www.motability.co.uk

**Muscular Dystrophy UK**

Charity providing services and resources to people with muscle wasting conditions, including muscular dystrophy.

Tel: 0800 652 6352, email: info@musculardystrophyuk.org
www.musculardystrophyuk.org

**National Autistic Society**

Offers information, resources and support to people with autism and their families. Also runs several specialist schools and care homes, a helpline and local support groups.

Helpline, tel: 0808 800 4104
Email: nas@nas.org.uk
www.autism.org.uk

**National Children’s Bureau (NCB)**

Campaigns to enable children and young people to fulfil their right to grow up safe, secure and supported so they can achieve their potential.

Tel: 020 7843 6000
Email: enquiries@ncb.org.uk
www.ncb.org.uk

**National Deaf Children’s Society (NDCS)**

Supports children and young people with hearing impairments and their families. Has online resources, a helpline, a forum and dedicated websites for children and young people.

Tel: 0808 800 8880
Email: helpline@ndcs.org.uk
www.ndcs.org.uk
Young people: www.buzz.org.uk

**National Eczema Society**

Provides independent and practical advice about treating and managing eczema. Has a helpline, fact sheets and runs local support groups.

Tel: 0800 089 1122
Email: helpline@eczema.org
www.eczema.org

**National Portage Association (NPA)**

Portage is a home visiting educational service for preschool children with SEND and their families. The NPA is the umbrella organisation for services, practitioners and parents.

Tel: 0121 244 1807
Email: info@portage.org.uk
www.portage.org.uk
National Talking Newspapers

Provision of audio-based newspapers and magazines in a variety of formats for blind and partially-sighted people.

Tel: 0303 123 9999
Email: helpline@rnib.org.uk
www.tnauk.org.uk

Newlife, the Charity for Disabled Children

Equipment providers for children with disabilities and life-limiting conditions. Also runs a helpline staffed by experienced nurses who can offer advice and support.

Tel: 0800 902 0095
Email: nurse@newlifecharity.co.uk
http://newlifecharity.co.uk

Patients Association

Helpline offering confidential information, advice and support about the health and social care system.

Tel: 020 8423 8999
www.patients-association.org.uk

Parliamentary and Health Service Ombudsman

Makes final decisions on complaints that have not been resolved by NHS England, UK government departments and other public organisations.

Helpline: 0345 015 4033
or text ‘call back’ and your name and phone number to: 07624 813005
www.ombudsman.org.uk

Newlife, the Charity for Disabled Children

Equipment providers for children with disabilities and life-limiting conditions. Also runs a helpline staffed by experienced nurses who can offer advice and support.

Tel: 0800 902 0095
Email: nurse@newlifecharity.co.uk
http://newlifecharity.co.uk

Patients Association

Helpline offering confidential information, advice and support about the health and social care system.

Tel: 020 8423 8999
www.patients-association.org.uk

PHAB

Recreational activities, specially equipped short breaks and holidays and clubs for children and adults with and without disabilities.

Tel: 020 8667 9443
Email: info@phab.org.uk
www.phab.org.uk

PINNT

Information, advice and support groups for patients on Intravenous and Nasogastric Nutrition Therapy, including advising parent carers on artificial nutrition for babies and children.

www.pinnt.com

Rainbow Trust

Support in hospital and at home for families who have a child aged 0 to 18 years with a life-threatening or life-limiting illness. Also offers bereavement support.
Tel: 01372 363438, email: enquiries@rainbowtrust.org.uk
www.rainbowtrust.org.uk

Reach

Membership-based organisation, providing information and support for children with upper limb differences.

Tel: 0845 130 6225 or 020 3478 0100
Email: reach@reach.org.uk
www.reach.org.uk

Remap

Tailor-made special equipment for disabled people, designed and built by expert volunteers.

Tel: 01732 760209
Email: data@remap.org.uk
www.remap.org.uk

Rett UK

Helpline, resources, local support groups and clinics at major hospitals for children and adults with Rett Syndrome.

Helpline: 01582 798911
Email: support@rettuk.org
www.rettuk.org

Riding for the Disabled

Umbrella organisation representing local volunteer groups that organise riding, carriage driving, showjumping and more for disabled children and adults.

Tel: 01926 492915
Email: info@rda.org.uk
www.rda.org.uk

Royal Brompton Hospital

London hospital that has a leading paediatric department for children and young people with respiratory illnesses, and congenital or acquired heart disease.

Tel: 020 7352 8121
www.rbht.nhs.uk/patients/childrens-services/

Royal National Institute of Blind People (RNIB)

Wide range of services including: information and advice; training and resources; research; regional support; and campaigning on behalf of people with sight loss.

Tel: 0303 123 9999
Email: helpline@rnib.org.uk
www.rnib.org.uk
SANDS

Charity supporting families affected by the death of a baby before, during or shortly after birth. Offers bereavement support, a helpline, online forum, network of support groups and online resources.

Tel: 0808 164 3332
Email: helpline@uk-sands.org
www.sands.org.uk

Sane

Charity offering support and care to people with mental health problems and their families/carers. Has a helpline and email service, an online forum and online resources.

Helpline: 0300 304 7000
Email: info@sane.org.uk
www.sane.org.uk

Scope

Charity for people with disabilities and their families and carers. Offers a helpline, information and advice and much more.

Tel: 0808 800 3333
Email: helpline@scope.org.uk
www.scope.org.uk

Scouts Association

Umbrella organisation representing the Scouting movement in the UK.

Tel: 0345 300 1818
Email: info.centre@scouts.org.uk
www.scouts.org.uk

Sense

Supports people who are deafblind, have sensory impairments or complex needs. Offers information and advice and specialist children’s services, summer holidays and short breaks.

Tel: 0300 330 9256 or 020 7520 0972
Email: info@sense.org.uk
www.sense.org.uk

Shine

Specialist support and online resources from before birth for people living with spina bifida and/or hydrocephalus and their families/carers.

Tel: 01733 555988, email: firstcontact@shinecharity.org.uk
www.shinecharity.org.uk
Shopmobility

National federation of Shopmobility schemes that allow disabled people to access wheelchairs and scooters in various shopping centres around the UK.

Tel: 01933 229644
Email: shopmobility@bhta.com
www.nfsuk.org

Sibs

Charity representing the needs of the siblings of disabled people. Provides direct support to young siblings through YoungSibs and has a network of adult sibling support groups.

www.sibs.org.uk
www.youngsibs.org.uk

Sickle Cell Society

Supports people affected by sickle cell disease. Website has a range of resources, a blog, newsletters and a dedicated area for children.

Tel: 020 8961 7795
Email: info@sicklecellsociety.org
www.sicklecellsociety.org

Signalong Group

Information, advice, training and research into the development of the Signalong system of communication.

Tel: 01634 727087
Email: admin@signalong.org.uk
www.signalong.org.uk

Southampton Children’s Hospital

Major centre for specialist paediatric services.

Tel: 023 8077 7222
Email: childrenshospital@uhs.nhs.uk
www.uhs.nhs.uk/Ourhospitals/SCH/SouthamptonChildrensHospital.aspx

Steps

Charity supporting people affected by childhood lower limb conditions such as talipes (club foot) and Perthes disease.

Tel: 01925 750271
Email: info@steps-charity.org.uk
www.steps-charity.org.uk

St George’s Hospital

London hospital offering specialist children’s services.

Tel: 020 8672 1255
www.stgeorges.nhs.uk/service/childrens-services-2/
Syndromes Without a Name (SWAN UK)

Dedicated support network for families of children and young adults with undiagnosed genetic conditions.

Tel: 020 7831 0883
Email: info@undiagnosed.org.uk
www.undiagnosed.org.uk

Together for Short Lives

Charity for children and young people with health conditions that are life-shortening or life-threatening.

Tel: 0808 808 8100, email: info@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk

Tourettes Action

Supports people with Tourette Syndrome and their families. Offers information and support, has a helpdesk, befriender network and support groups.

Tel: 0300 777 8427
www.tourettes-action.org.uk

Tourism for All

Information and advice that ensures travel and leisure is accessible to all. Also operates a directory of comprehensive information about accessible accommodation, attractions and places to eat and drink throughout the UK.

Tel: 0845 124 9971
Email: info@tourismforall.org.uk
www.tourismforall.org.uk
www.openbritain.net

Unique (Rare Chromosome Disorder Support Group)

Information for families and individuals affected by rare chromosome disorders.

Tel: 01883 723356
Email: info@rarechromo.org
www.rarechromo.org

Whizz-Kidz

Provides mobility equipment, skills training and opportunities for disabled children and young people to meet and socialise.

Tel: 020 7233 6600
Email: info@whizz-kidz.org.uk
www.whizz-kidz.org.uk
Working Families

Advice for working parents and carers on topics such as employment rights, in-work benefits, flexible working options. Includes a separate section for parents of disabled children.

Tel: 0300 012 0312, email: advice@workingfamilies.org.uk  
www.workingfamilies.org.uk

Young Epilepsy

Charity for children and young people with epilepsy and associated conditions. Offers advice on diagnosis, treatment and living with epilepsy.

Tel: 01342 831342  
Email: info@youngepilepsy.org.uk  
www.youngepilepsy.org.uk

Young Minds

Supports the wellbeing and mental health of children and young people. Includes information resources on a range of mental health conditions and a parent helpline.

Parents' helpline: 0808 802 5544  
www.youngminds.org.uk
STATE-MAINTAINED SPECIAL SCHOOLS

Chailey Heritage School (out-of-county)
A charitable special school for children and young people aged three to 19 years with complex physical disabilities, high health needs, sensory impairments and associated communication and learning difficulties.

Haywards Heath Road
North Chailey
Lewes, East Sussex
BN8 4EF
Tel: 01825 724444
Email: office@chf.org.uk
www.chf.org.uk

Cornfield School
A school for boys and girls aged nine to 16 who have social, emotional and/or behavioural difficulties.

Cornfield Close, Wick
Littlehampton, BN17 6HY
Tel: 01903 731277, email: office@cornfieldschool.org.uk
www.cornfield.w-sussex.sch.uk

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.fordwater.myedupress.co.uk

Herons Dale Primary School
A generic primary school for children aged four to 11 with a wide spectrum of learning difficulties.

Hawkins Crescent
Shoreham-by-Sea, BN43 6TN
Tel: 01273 596904
Email: office@heronsdale.co.uk
www.heronsdale.co.uk

Littlegreen School
For boys aged seven to 16 who have social, emotional, mental and/or behavioural difficulties; autism or Asperger’s syndrome. Boarding provision.

Compton, Chichester
PO18 9NW
Tel: 023 9263 1259, email: office@littlegreenschool.co.uk
www.littlegreen.w-sussex.sch.uk
Manor Green College
Secondary school for students aged 11 to 19 who experience a wide range of learning difficulties.

Lady Margaret Road
Ifield, Crawley
RH11 0DX
Tel: 01293 520351
Email: office@mgcollege.co.uk
http://www.manorgreen-college.w-sussex.sch.uk/web

Manor Green Primary School
Caters for pupils aged from two to 11 years with a wide range of learning difficulties.

Lady Margaret Road
Ifield, Crawley, RH11 0DU
Tel: 01293 526873, email: office@manorgreenprimary.w-sussex.sch.uk
www.manorgreenprimary.w-sussex.sch.uk

Oak Grove College
A secondary school providing special education for students with learning difficulties from 11 to 16 years.

The Boulevard
Worthing, BN13 1JX
Tel: 01903 708870, email: office@oakgrove.w-sussex.sch.uk
www.oakgrovecollege.org.uk

Palatine Primary School
Primary school for children with complex needs, including: severe learning difficulties, profound and multiple learning difficulties, moderate learning difficulties and autistic spectrum conditions.

Palatine Road, Goring-by-sea, Worthing, BN12 6JP
Tel: 01903 242835
Email: office@palatineschool.org
www.palatineschool.org

Queen Elizabeth II Silver Jubilee School
Caters for two to 19 year olds with severe or profound and multiple learning difficulties or complex needs.

Comptons Lane
Horsham, RH13 5NW
Tel: 01403 266215, email: office@queenelizabeth2.w-sussex.sch.uk
www.queenelizabeth2.w-sussex.sch.uk

St Anthony’s School
Community special school for five to 16 year olds with moderate or complex needs.

Woodlands Lane
Chichester, PO19 5PA
Tel: 01243 785965
Email: office@st-ants.org
www.st-ants.org
Woodlands Meed College

For young people aged 14 to 19 with special educational needs.

Birchwood Grove Road,
Burgess Hill, RH15 0DP
Tel: 01444 244133
Email: office@woodlandsmeed.co.uk
www.woodlandsmeed.co.uk

Woodlands Meed School

Special needs school for children aged two to 14 years with a wide range of special educational needs.

Chanctonbury Road
Burgess Hill, RH15 9EY
Tel: 01444 244133
Email: office@woodlandsmeed.co.uk
www.woodlandsmeed.co.uk

INDEPENDENT AND SECTION 41 SPECIAL SCHOOLS

Brantridge School

Day and residential school for boys aged six to 13 with social, emotional and mental health difficulties, autism, Asperger’s syndrome, ADHD or specific learning difficulties such as dyslexia.

Staplefield Place, Staplefield,
Haywards Heath, RH17 6EQ
Tel: 01444 400228, email:
schooloffice@brantridge-school.co.uk
http://brantridge-school.co.uk

Farney Close School Ltd

A mixed residential and day secondary school for children aged 11 to 14 years with social, emotional and behavioural difficulties. Also supports pupils with Asperger’s and 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 16+ years with neurological motor impairments such as cerebral palsy. Pupils have a range of abilities and associated learning difficulties.

Five Oaks, Billingshurst
RH14 9AX
Tel: 01403 782294
Email: ingfield.manor@scope.org.uk
www.scope.org.uk/support/services/education/ingfield-manor-school
Muntham House School

Residential and day school for boys aged eight to 19 years who have emotional and social difficulties with mental health problems, autism or ADHD.

Barns Green, Horsham
RH13 0NJ
Tel: 01403 730302
Email: office@muntham.org.uk
www.muntham.org.uk

Philpots Manor School

Day and residential school for children and young people aged from seven to 19 who have a range of social, emotional, behavioural, or communication difficulties.

West Hoathly, RH19 4PR
Tel: 01342 810268, email: info@philpotsmanorschool.co.uk
www.philpotsmanorschool.co.uk

Seadown School

For children and young people aged six to 16 with a variety of special educational needs including moderate learning difficulties, dyslexia, autistic spectrum disorder, ADHD and behavioural, emotional and social difficulties.

1a Farncombe Road, Worthing
BN11 2BE
Tel: 01903 608750, email: amanda.curry@seadownschool.co.uk
http://seadownschool.co.uk/

Springboard Education

For children and young people aged five to 18 with emotional, behavioural, social and communication difficulties including autism and attention deficit conditions.

55 South Street, Lancing,
BN15 8AN
Tel: 01903 605980 or 01903 885109
Email: office@springboardeducation.co.uk
www.springboardeducation.co.uk

SPECIAL SUPPORT CENTRES
WITHIN MAINSTREAM NURSERY SCHOOLS

Boundstone Nursery School
(Speech and Language Unit)

Special Support Centre for young children with significant speech and language difficulties.

Upper Boundstone Lane
Lancing, BN15 9QX
Tel: 01903 276850
Email: office@bnscfc.co.uk
www.boundstone-lancingcfc.co.uk
SPECIAL SUPPORT CENTRES WITHIN MAINSTREAM PRIMARY SCHOOLS

Barnham Primary School
Special school support facility, known as The Orchard, for up to ten children from the western and southern areas of West Sussex, who have physical disabilities and/or speech and language needs.

Elm Grove
Barnham, PO22 0HW
Tel: 01243 552197, email: office@barnhamprimaryschool.co.uk
www.barnhamprimaryschool.co.uk

Blackthorns Community Primary School (Special Support Centre)
Blackthorns has a Special Support Centre for children with Education Health and Care Plans for specific learning difficulties, additional needs and speech and language difficulties.

3 Blackthorns Close
Lindfield, RH16 2UA
Tel: 01444 454866, email: office@blackthornsprimaryacademy.org.uk
www.blackthornsprimaryacademy.org.uk

Desmond Anderson Primary Academy (Special Support Centre)
Special Support Centre for children with autism spectrum conditions or social and communication needs.

Anderson Road
Crawley, RH10 5EA
Tel: 01293 525596, email: office@desmondandersonprimaryacademy.org.uk
http://desmondandersonprimaryacademy.org.uk

Durrington Infant and Junior Federated Schools (Social Communication Unit)
Durrington has a Special Support Centre for children with autism spectrum conditions or social and communication difficulties.

Salvington Road
Worthing, BN13 2JD
Tel: 01903 260761 or 01903 260138
Email: enquiries@dfed.co.uk
www.durringtoninfantjunior.co.uk

Field Place Infant School (Speech and Language Unit)
Special Support Centre for children with speech, language and communication needs.
Nelson Road
Goring By Sea, Worthing
BN12 6EN
Tel: 01903 700234
Email: office@fieldplace.org.uk
http://fieldplace.greenschoolsonline.co.uk

London Meed Community Primary
School (Speech and Language Unit)

Special Support Centre for children with severe speech and language difficulties as their primary need. They may also have additional physical, medical, cognitive, social and emotional needs.

Chanctonbury Road
Burgess Hill, RH15 9YQ
Tel: 01444 232336, email: office@londonmeedprimary.co.uk
www.londonmeedprimary.co.uk

Lyndhurst Infant School
(Special Support Centre)

Special Support Centre for children with autism or social communication difficulties.

Lyndhurst Road
Worthing, BN11 2DG
Tel: 01903 235390, email: office@lyndhurst-school.co.uk
www.lyndhurstfirstschool.co.uk

Maidenbower Junior School
(Additional Learning Needs)

Special Support Centre for children with a specific learning difficulty such as dyslexia or speech and language needs.

Harvest Road, Maidenbower
Crawley, RH10 7RA
Tel: 01293 883758, email: office@maidenbowerjunior.w-sussex.sch.uk
www.maidenbowerjunior.co.uk

Northgate Primary School
(Hearing Impaired Unit)

The Orchard is a Special Support Centre within the school for children with hearing impairments.

Green Lane
Crawley, RH10 8DX
Tel: 01293 526737, email: office@northgate.w-sussex.sch.uk
www.northgate.w-sussex.sch.uk

Steyning C of E Primary School
(Speech and Language Unit)

Special Support Centre for children with severe and specific speech and language disorders.

Shooting Field
Steyning, BN44 3RQ
Tel: 01903 813420, email: office@steyningprimary.w-sussex.sch.uk
www.steyningprimary.org.uk
St Margaret’s C of E Primary School
(Physical Disability Unit)

Special Support Centre catering for children with significant physical or medical needs.

The Mardens, Ifield
Crawley, RH11 0AQ
Tel: 01293 521077, email: office@st-margaretsifield.w-sussex.sch.uk
www.st-margaretsifield.w-sussex.sch.uk

Three Bridges Primary School
(Speech and Language Unit)

Special Support Centre for children with specific speech and language difficulties.

Lower site: Gales Place
Three Bridges, RH10 1QG
Upper site: Gales Drive, Three Bridges, RH10 1PD
Upper & lower site tel: 01293 524076
Email: office@threebridgesprimaryschool.co.uk
www.threebridgesprimaryschool.co.uk

West Park CE Primary School

Has two Special Support Centres; one for children with disabilities and another for those with additional learning needs.

Marlborough Road, Goring-by-sea Worthing, BN12 4HD
Tel: 01903 243099
Email: office@westparksch.co.uk
www.westpark.w-sussex.sch.uk

SPECIAL SUPPORT CENTRES WITHIN MAINSTREAM SECONDARY SCHOOLS

Angmering School
(Lavinia Norfolk Centre)

Secondary school for students aged 11 to 18. The Lavinia Norfolk Centre supports students with a variety of special needs and disabilities covering physical, medical or sensory impairment; autism; social communication difficulties; behavioural, social and emotional difficulties; specific or general learning difficulties.

Station Road, Angmering, BN16 4HH
Tel: 01903 772351, email: office@theangmeringschool.co.uk
www.angmeringschool.co.uk/students/learning-support/

Hazelwick School
(Sensory Support Centre)

Caters for young people aged from 11 to 19. The Sensory Support Centre is for children with hearing or visual impairment.
Hazelwick Mill Lane, Three Bridges
Crawley, RH10 1sX
Tel: 01293 403344
Email: office@hazelwick.org.uk
www.hazelwick.org

Oriel High School
(Additional Learning Needs)
Special Support Centre for children with severe dyslexia or speech and language difficulty.
Maidenbower Lane, Maidenbower
Crawley, RH10 7XW
Tel: 01293 880350
Email: office@oriel.w-sussex.sch.uk
www.oriel.w-sussex.sch.uk

Steyning Grammar School
(Additional Learning Needs)
Day and residential school catering for young people aged 11 to 18. A special needs team supports pupils with additional educational needs.
Lower school:
Church Street, BN44 3LB
Lower school tel: 01903 814786

Upper school & sixth form:
Shooting Field, BN44 3RX
Upper school tel: 01903 814555

Email: sgs@sgs.uk.net
www.sgs.uk.net

Thomas Bennett Community College (Social Communication Unit)
Ashdown Drive, Tilgate
Crawley, RH10 5AD
Tel: 01293 526255, email: admin@thomasbennett-tkat.org
www.thomasbennett-tkat.org

Warden Park Secondary Academy
(Additional Learning Needs)
Special Support Centre for children with severe specific learning difficulties, speech and language needs and additional learning needs.
Broad Street, Cuckfield
Haywards Heath, RH17 5DP
Tel: 01444 457881
Email: admin@wardenpark.co.uk
www.wardenpark.co.uk

Worthing High School
Caters for young people aged 11 to 16. Has a Special Support Centre for children with additional learning needs.
South Farm Road
Worthing, BN14 7AR
Tel: 01903 237864
Email: achieve@worthinghigh.net
www.worthinghigh.net
EDUCATIONAL ORGANISATIONS

ACE Education Advice and Training
Provides independent information, advice and support on state education in England.

72 Durnsford Road
London, N11 2EJ
Tel: 0300 011 5142
Email: enquiries@ace-ed.org.uk
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

Alternative Provision College (APC)
Sited in eight separate locations – Chichester; Crawley; Burgess Hill; Haywards Heath; Lancing; Littlehampton; Worthing; and a secure unit near Crawley. It offers educational provision to children and young people who have been permanently excluded, those at risk of exclusion, those out of school for medical reasons and those too sick to attend school.

http://apcollege.co.uk/contact

Autism and Social Communication Team
Specialist advisory teachers who work with staff (and parent carers) in mainstream schools to support children with ASD or social and communication difficulties. Referrals need to come via mainstream school SENCOs or staff.

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 in support of inclusive education.

Tel: 0117 353 3150
Email: admin@csie.org.uk
www.csie.org.uk

ClearVision
Postal lending library of mainstream children’s books in print and braille, and tactile books.
The Dame Vera Lynn Trust School for Parents

Specialist setting for young children (birth to five years) with cerebral palsy or motor learning difficulties.

Tel: 01444 473 274  
Email: info@dvlcc.org.uk  
www.dvlcc.org.uk

Down Syndrome Education International

Information, advice and research to improve education for young people with Down syndrome.

6 Underley Business Centre  
Kirkby Lonsdale, Cumbria  
LA6 2DY  
Tel: 0330 043 0021  
Email: hello@dseinternational.org  
www.dseinternational.org

Educational Psychology Service

Works with children, parents and schools to improve children’s learning and development. Referrals via the Special Educational Needs team at the local authority.

Global Mediation

Provides mediation for numerous issues, including disputes concerning children with SEND.

Area Education Office  
Centenary House  
Durrington Lane  
Worthing, BN13 2QB  
Tel: 01903 839308, email: cate.mullen@westsussex.gov.uk

Ethnic Minority and Traveller Achievement Support (EMTAS)

Works with West Sussex schools to raise the attainment of Black and Minority Ethnic (BME), Gypsy Roma Traveller (GRT) and bilingual pupils.

BME and EAL (English as an Additional Language) queries (EMAT):  
Tel: 0330 222 2111  
Email: emat@westsussex.gov.uk  
Traveller Education queries (TES):  
Tel: 0330 222 2155  
Email: tes@westsussex.gov.uk  
http://schools.westsussex.gov.uk/Services/3381

Global Mediation

Provides mediation for numerous issues, including disputes concerning children with SEND.

Tel: 0800 064 4488  
Email: info@globalmediation.co.uk  
www.globalmediation.co.uk
Independent Parental Special Education Advice (IPSEA)

Information, resources and legal advice on education issues, appeals and tribunals. You can book a call back from the advice line on the website.

www.ipsea.org.uk

Learning and Behaviour Advisory Team (LBAT)

Specialist advisory teachers who work with children, families and schools to improve children’s educational outcomes and emotional well-being. Referrals via mainstream school SENCOs or staff.

Tel: 0330 222 8519, email: denise.snook@westsussex.gov.uk
https://westsussex.local-offer.org/services/229

Listening Books

Postal and internet-based library service providing audio books for people of all ages who find it difficult or impossible to read owing to illness or disability.

Tel: 020 7407 9417
Email: info@listening-books.org.uk
www.listening-books.org.uk

National Association for Special Educational Needs (NASEN)

Promotes the education, training, advancement and development of all those with SEND and additional learning needs.

Tel: 01827 311500
Email: welcome@nasen.org.uk
www.nasen.org.uk

National Institute of Conductive Education

Workshops, training and outreach services on the principles and methods of conductive education for children, adults, and their families.

Tel: 0121 449 1569
Email: foundation@conductive-education.org.uk
www.conductive-education.org.uk

Network 81

Information, advice, training and support for parents on issues around special educational needs.

Tel: 0845 077 4055
Email: advice@network81.org.uk
www.network81.org.uk
Office for Standards in Education (OFSTED)

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

Parents for Inclusion

Network of parents of children with SEND. Campaigns for inclusion in education. Provides information, advice, and training.

Email: info@parentsforinclusion.org
www.parentsforinclusion.org

Pre-School Learning Alliance

Supports childcare providers and parents to help families access high quality early learning opportunities. Information, advice, training and support for parents and professionals.

Tel: 020 7697 2595
Email: info@pre-school.org.uk
www.pre-school.org.uk

Pupil Entitlement: Investigation

Works with school and families to ensure high levels of school attendance.

Tel: 0330 222 8200

Special Educational Needs and Disability Tribunal (SENDIST)

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

Supports children and young people aged from birth to 19 with hearing, visual or multi-sensory impairment.

Tel: 01903 270430, email: sensory.support@westsussex.gov.uk
www.westsussex.gov.uk/education-children-and-families
SEND HUB NETWORKS

SEND Hub Networks enable schools and other organisations to share expertise locally and access support for children and young people with SEND aged 0 to 25. If you feel your child needs additional support, speak to your child’s school to see what your local SEND Hub Network can offer.

**Adur (Hive)**

Email: support@adurhive.com
www.adurhive.com

**Angmering (Angmering ASCEND)**

Angmering School
Tel: 01903 772351, email: office@theangmeringschool.co.uk

East Preston Junior
Tel: 01903 785672
Email: office@epjs.co.uk

Georgian Gardens Primary
Tel: 01903 771555, email: office@georgiangardens.w-sussex.sch.uk

**Billingshurst (Weald SEND Alliance)**

Email: enquiries@wealdsendalliance.org.uk
http://wealdsendalliance.org.uk

**Burgess Hill and Hassocks (The Meeds SEND Alliance)**

Email: SENDAlliance@woodlandsmeed.co.uk
www.woodlandsmeed.co.uk

**Chichester, Bognor and surrounding areas (NOVIO)**

Email: info@noviosupport.org
www.noviosupport.org

**Crawley (Manor Green)**

Manor Green College
Tel: 01293 520351
Email: office@mgcollege.co.uk

**East Grinstead (NEST)**

Email: enquiries@nestsend.org.uk
www.nestsend.org.uk

**Horsham (Compass@QEII)**

Email: compass@queenelizabeth2.w-sussex.sch.uk
www.compass-support.org

**Littlehampton (Shell)**

c/o St Catherine’s Catholic Primary
Tel: 01903 716039, email: office@st-catherines.w-sussex.sch.uk
Midhurst and Petworth (Rother Valley Inclusion)
Email: enquiries@rvhub.org.uk
www.rvhub.org.uk

Storrington and Steyning (Chanctonbury and Stars)
Jolesfield C of E Primary
Tel: 01403 710546, email: office@jolesfield.w-sussex.sch.uk

Upper Beeding Primary
Tel: 01903 812288, email: office@upperbeeding.w-sussex.sch.uk

Worthing and Durrington (WAVE)
Tel: 01903 241368
Email: pwalker@chathigh.co.uk
https://sites.google.com/site/wavesendhubpublic/
3H Fund

Grants are awarded to disabled people on a low income and their families and carers to take holidays in the UK. To request an application form call the fund on the number below.

Tel: 01892 860207
Email: info@3hfund.org.uk
www.3hfund.org.uk

ACT Foundation

Grants are awarded towards building costs, specialised equipment and the costs of a short-term respite break. Individuals must apply via an application form available for download on the website.

Tel: 01753 753900
Email: info@theactfoundation.co.uk
www.theactfoundation.co.uk

Action for Kids

Provides mobility equipment for children and young people aged under 26. To discuss making an application call the helpline below.

Tel: 020 8347 8111
www.actionforkids.org

Argus Appeal

Provides grants to lonely and needy older people and under-privileged children facing sickness, poverty, and hardship, particularly at Christmas. For further information on criteria and how to apply, visit the website below.

Tel: 01273 544465
Email: elsa.gillio@theargus.co.uk
www.resourcecentre.org.uk

Ataxia UK

Manages a number of grants to help people with ataxia to fund things such as aids, home adaptations and travel. For further information visit the website.

Tel: 0845 644 0606
Email: helpline@ataxia.org.uk
www.ataxia.org.uk

British Kidney Patient Association (BKPA)

Provides grants to children and adults with kidney disease. Grants can be for domestic bills, household goods, travel expenses to hospital, education and training costs and holidays. Application forms are available to download from the charity’s website.

Tel: 0845 644 0606
Email: helpline@bkpa.org.uk
www.bkpa.org.uk

www.actionforkids.org

www.ataxia.org.uk

www.resourcecentre.org.uk

www.bkpa.org.uk
Buttle UK

Supports disadvantaged children and young people. Grants are for essential household items, for the cost of school fees of children whose home life is precarious and for young people in further education, or to help young people not in education, employment or training. For further information on individual grant programmes and how to apply visit the website listed below.

Tel: 020 7828 7311
www.buttleuk.org

Bruce Wake Charitable Trust

Grants are awarded towards the provision of sport and leisure activities for wheelchair users. Applications on behalf of individuals must be made through a charitable organisation or equivalent recognised body. Grant applications are considered quarterly. Guidelines on how to apply are available from the trust’s website.

Tel: 01382 204446
Email: bbs@brittlebone.org
www.brittlebone.org

Brittle Bone Society

Provides grants for wheelchairs or specialist equipment for people with brittle bone disease. Initial enquiries should be made by phone or email. Grant applications must include a letter of support from a relevant professional such as an occupational therapist, for example.

Tel: 01420 541424
Email: info@britishkidney-pa.co.uk
www.britishkidney-pa.co.uk

Buttle UK

Supports disadvantaged children and young people. Grants are for essential household items, for the cost of school fees of children whose home life is precarious and for young people in further education, or to help young people not in education, employment or training. For further information on individual grant programmes and how to apply visit the website listed below.

Tel: 020 7828 7311
www.buttleuk.org

B.V. MacAndrew Trust

Provides grants to help poor or disabled young people get a good start in life. Applications via an intermediary charity or suitable organisation should be made in writing to the trustee listed below.

Roger Heber Clow
Trustee
9 Albert Mews
Third Avenue
Hove, BN3 2PP
Tel: 01273 562563
Carer Wellbeing Fund

Funding to enable carers to do something to enhance their health and wellbeing. The maximum amount a carer can apply for in any 12 month period is £300. You can apply via Carers Support West Sussex or the West Sussex Parent Carer Forum.

Tel: 0300 028 8888
Email: info@carerssupport.org.uk
www.carerssupport.org.uk

Chichester Welfare Trusts

Provides grants for people who are in need, sick, disabled or infirm and live in the city of Chichester.

Tel: 01243 789539, email: clerk@chichesterwelfaretrusts.org.uk
www.chichesterwelfaretrusts.org.uk

Caudwell Children

Provides funding towards equipment, (including sports equipment) treatment and therapies for children with various disabilities and illnesses in the UK, and holidays for children with life-threatening conditions. For further information visit the website listed below.

Tel: 0345 300 1348, email: charity@caudwellchildren.com
www.caudwellchildren.com

Cheyne Charity for Children with Cerebral Palsy

Provides grants to families of children and young people with cerebral palsy towards the cost of essential equipment and respite breaks. It helps if your application is supported by a professional such as a physiotherapist or doctor. For further information please visit the website.

Tel: 01444 450901
www.cheynecharity.org

Child Brain Injury Trust (CBIT)

Provides small grants, up to a maximum of £100, for children with brain injuries and their siblings to take part in social activities. Also administers the Mary Radnoti-Dwyer Education Assessment Grant, which can provide a one-off payment of up to £350 towards a professional report for an EHC Assessment or appeal to the local authority. Guidelines and an application form are available from the trust’s website.

Tel: 0303 303 2248
Email: info@cbituk.org
https://childbraininjurytrust.org.uk
Children’s Heart Federation

Provides grants for travel costs while a child is in hospital, home appliances, and specialist equipment. Application forms are available from the charity’s website or by phoning the number listed below. Application forms need to be completed by a professional who knows your circumstances.

Tel: 0808 808 5000
Email: info@chfed.org.uk
www.chfed.org.uk

Children Today

Provides grants towards specialised equipment such as electric wheelchairs, walking aids, trikes, sensory equipment, adapted car seats, lifting aids and posturepedic sleep equipment for children and young people with disabilities. For further information call the charity on the number given below.

Tel: 01244 335622
Email: info@childrentoday.org.uk
www.childrentoday.org.uk

Disabled Facilities Grant

Local council funding towards the costs of adapting the home and/or to provide better facilities within it in order to allow disabled people to continue living in the property. Maximum grant in England is £30,000. Disabled young people under 18 can get a grant without their parents’ income being taken into account. For further information contact the housing or environmental health department of your local council.

www.gov.uk/disabled-facilities-grants/overview

Dreams Come True

Provides funding and support to help children and young people aged 2 to 21 who have a serious or life-limiting medical condition to fulfil their dreams. To nominate a child, please read the guidelines and complete the online application form at the website listed below.

Tel: 0800 018 6013, email: info@dreamscometrue.uk.com
www.dreamscometrue.uk.com

Family Action

Provides welfare and educational grants to families on benefits or low incomes. Guidelines and applications forms are available to download from the charity’s website.

Tel: 020 7254 6251, email: grants.enquiry@family-action.org.uk
www.family-action.org.uk
Family Fund

Provides grants to families with a disabled child or young person eligible for one or more of the following: Universal Credit, Child Tax Credit; Working Tax Credit; Income-based Job Seekers Allowance; Income Support; Incapacity Benefit; Employment Support Allowance; Housing Benefit; and Pension Credit. If you are not in receipt of any of these benefits, you will need to provide additional information and evidence of your whole household income and the Fund will contact you after you have applied.

Grants can be used for a wide variety of purposes including washing machines, cookers, beds, outings and holidays, and specialist equipment. Further information on eligibility and how to apply are on the Fund’s website.

Tel: 01904 550055
Email: info@familyfund.org.uk
www.familyfund.org.uk

Family Holiday Association

Provides funding to enable families on low incomes with children under 18 to have a holiday. Applications must be made by referral from a welfare agent, for example social worker, health visitor, or GP. Applications for a holiday for families with a disabled child will only be considered if they are not eligible for a grant from the Family Fund. However, they can be referred for a group trip or day out. Further information on how to apply is available from the organisation’s website.

Tel: 020 3117 0650, email: info@FamilyHolidayAssociation.org.uk
www.familyholidayassociation.org.uk

Florence Nightingale Aid in Sickness Trust

Provides grants to people of all ages who are sick, in poor health or disabled and require medical services and/or equipment to improve their quality of life. Funding available for convalescent and respite care, medical aids, household aids, sensory equipment, communication aids, fridges for essential drug storage, and more. Applications are available to download from the trust’s website or by phoning the number below. Applications need to be completed by a relevant professional, for example, GP, social worker or healthcare professional. Grants will only be considered where it has been confirmed that funding cannot be provided by the local authority or NHS.

Tel: 020 7998 8817
Email: ann.griffiths@fnaist.org.uk
http://fnaist.org.uk/
Gardener’s Trust for the Blind

Grants for a variety of purposes including education, training and household maintenance for people who are blind or partially sighted. Grants for pensions may also be considered.

Grant making guidelines do not appear to be available, so we would recommend making an initial enquiry in writing, enclosing confirmation of disability from a third party.

The Gardners Trust for the Blind
117 Charterhouse Street
London, EC1M 6AA
Tel: 020 7253 3757

Glasspool Charity Trust

Provides grants to individuals for the relief of poverty, distress, ill-health or disability. Applications must be made via an eligible agency, for example, a charity. Grants can be as low as £50 or as high as £5,000. Guidelines and details of the application process are available from the trust on request.

Tel: 020 3141 3161
Email: grants@glasspool.org.uk
www.glasspool.org.uk

Guide Dogs – Children and young people’s services

Provides grants towards technology or sensory items which are in support of the charity’s aims and where no source of statutory funding will pay for the item required. Grants are for children and young people aged 18 and under. All grant applications need to be endorsed by a qualified professional working in the field of visual impairments, for example, a social worker or QTVI teacher. Visit the website for more information.

Tel: 0800 781 1444, email: cypservices@guidedogs.org.uk
www.guidedogs.org.uk

Happy Days Children’s Charity

Provides grants towards the costs of day trips, outings and holidays for disadvantaged children and young people aged from three to 17 years and their families. Guidelines state that grants are awarded to young people who have special educational needs or life-limiting conditions. Further details on grant programmes and how to apply are available on the charity’s website.

Tel: 01582 755999, email: enquiries@happydayscharity.org
www.happydayscharity.org
Joseph Patrick Trust

Provides grants for wheelchairs, mobility equipment, therapy equipment and discretionary payments for the ‘relief of stress’ to people with muscular dystrophy. Further information is available on the Muscular Dystrophy UK website listed below.

Tel: 0800 652 6352, email: info@musculardystrophyuk.org
www.musculardystrophyuk.org

Lawrence Atwell’s Charity (Skinners’ Company)

Provides grants towards vocational training and the costs of getting a job for young people from low-income families. Priority is given to young people with additional barriers in life, including disabilities. Further details on how to apply are available on the website listed below.

Tel: 020 7236 5629
Email: atwell@skinners.org.uk
www.theskinnerscompany.org.uk

League of the Helping Hand

Grants are provided to people in financial hardship owing to disability or illness, including carers of children with special needs. An application form, which must be completed by an official agency such as social services, can be downloaded from the charity’s website.

Tel: 01444 236099
Email: secretary@lhh.org.uk
www.lhh.org.uk

Lifeline 4 Kids

Provides specialist equipment like electric wheelchairs, mobility aids and computer equipment for children with disabilities from birth to 18. Cash grants are not awarded. Please read the specific criteria on the website address below and then send the information they request by email.

Email: appeals@lifeline4kids.org
www.lifeline4kids.org

Margaret Champney Rest and Holiday Fund

Small grants for carers primarily in order to take a short break or holiday. Applications must be made via a social worker, community nurse or other relevant professional. Please see the web page below for information that should be emailed to the Fund by your chosen professional.

Tel: 01394 388746
Email: info@ogilviecharities.org.uk
www.ogilviecharities.org.uk
Miracles

Provides crisis grants to children and families ‘who fall through the net of other aid agencies’. Grants are awarded to single parents with one or more sick/disabled dependants; parents/carers with two or more sick/disabled dependants; for hospital transport and accommodation where no other funding is available; additional medical needs, equipment, special diets, special clothing; respite breaks and ‘treats after treatment’. For further information, we suggest making an enquiry directly to the charity.

PO Box 3003
Littlehampton, BN16 1SY
Tel: 01903 775673
www.miraclesthecharity.org

Mobility Trust

Provides funding towards the purchase of powered wheelchairs and scooters for disabled people who cannot obtain one from statutory sources or purchase the equipment themselves. Please see the web page below to check whether you are eligible for a grant. You can apply by phoning one of the numbers below or by writing or emailing the Trust, giving details of the person’s disability and why the equipment is needed.

Tel: 0118 984 2588 or 0118 466 0195,
email: mobility@mobilitytrust.org.uk
www.mobilitytrust.org.uk

Motability

Provides grants towards the costs of purchasing a car, adaptions like swivel seats or hand controls and driving lessons for young people aged 16 to 24. The web page below explains the eligibility criteria. For further information on how to apply, call the customer services team on the number listed below.

Motability also administers a government grant programme for people who need a wheelchair accessible vehicle.

Tel: 0300 456 4566
www.motability.org.uk

Newby Trust

Grants of up to £250 are provided to ensure the basic needs of individuals and families living on benefits or a low income are met. Applications must be made online and be submitted by social services or a similar organisation. See the website for full details.

Email: info@newby-trust.org.uk
www.newby-trust.org.uk/on-behalf-of-an-individual/
Newlife, the Charity for Disabled Children

Provides grants towards the costs of equipment for disabled children and young people under the age of 18. For further information contact the care services team on the number listed below.

Tel: 0800 902 0095
Email: nurse@newlifecharity.co.uk
http://newlifecharity.co.uk

React

Provides grants to families caring for a child with a life-threatening or life-limiting illness. Funding is available towards specialist medical equipment not available through the NHS, educational equipment, domestic equipment that helps contribute towards a child’s quality of life and hospital expenses (including travel, food or related costs). React can also provide free holidays at one of their holiday homes. Application forms and further information are available to download from the charity’s website, or you can phone the number below to request them.

Tel: 020 8940 2575
Email: react@reactcharity.org
https://reactcharity.org

Roald Dahl’s Marvellous Children’s Charity

Provides grants to help families in financial hardship who are caring for a child/young person with a serious illness. The maximum grant is £500 and can be spent in different ways including towards the cost of mobility equipment, specialist furniture or household appliances, utility bills, travel and subsistence costs. Applications must be made by a professional who knows the family, such as a specialist nurse or social worker, who should phone the number below. Guidelines are available on the charity’s website.

Tel: 01494 890465
www.roalddahl.com

Sequal Trust

Fundraises for the purchase of communications aids for children and adults who are severely disabled. An application can be completed online at the trust’s website.

Tel: 01691 624222
Email: info@thesequaltrust.org.uk
http://thesequaltrust.org.uk
Starlight Children’s Foundation

Grants personalised wishes to children and young people aged four to 18 with life-threatening or life-shortening illnesses. To nominate a child, complete the wish application form on the charity’s website.

Tel: 020 7262 2881
www.starlight.org.uk

Stars Foundation for Cerebral Palsy

Provides grants towards mobility equipment and communication aids for people with cerebral palsy. For further information email or write to the charity at the address below.

Mr Michael Norman FCA, ACIS, Marlings, Camden Park, Tunbridge Wells, TN2 4TN

Tel: 01892 539283
Email: info@starsfoundation.co.uk
www.starsfoundation.co.uk

Sullivan’s Heroes

Charity offering support for families seeking to raise funds for home adaptations to meet the needs of a disabled child where the costs of the project exceed that of the government Disabled Facilities Grant (DFG). Provides financial grants and fundraising assistance to enable families to raise money for their own adaptations project. Application forms can be downloaded from the website.

Email: hello@sullivansheroes.org
www.sullivansheroes.org
www.facebook.com/sullivansheroes

Sure Start Maternity Grant

Government grants towards the cost of a new baby for people on low incomes and certain benefits. Can apply if your baby is due within 11 weeks, was born in the last three months, or if you’re not a birth parent but have become responsible for a child under a year old. Maximum grant is £500. For further information and full eligibility criteria, please go to the following website.

www.gov.uk/sure-start-maternity-grant

Sussex Association for Spina Bifida & Hydrocephalus (SASBAH)

Provides grants to its service users where no statutory help is available to purchase accessible household appliances or mobility equipment. For further information, please visit the charity’s website or phone or email them.

Tel: 01825 873045
Email: rom@sasbah.org.uk
www.sasbah.org.uk
**Sussex Snowdrop Trust**

Provides financial support to families of children with life-threatening illnesses. Funding can be used towards a wide variety of purposes including: household bills; specialist equipment; computers; and transport costs. For further information on eligibility and catchment area, visit the website listed below.

Tel: 01243 572433, email: info@thesussexsnowdroptrust.com
www.thesussexsnowdroptrust.com

**Talisman Charitable Trust**

Grants to help with education, health, housing and disabilities to UK individuals described as ‘going short’. Applications should be made via another charitable organisation, local authority or Citizens Advice Bureau. Guidelines on how to apply are available on the charity’s website.

www.talismancharity.org

**Tourettes Action**

Grants of up to £500 available to improve the quality of life of people with Tourette syndrome. Application form and guidelines are available on the charity’s website or by calling the number below.

Tel: 0300 777 8427
Email: help@tourettes-action.org.uk
www.tourettes-action.org.uk

**Tree of Hope Children’s Charity**

Provides professional support and resources for families to raise money for specialist care for their disabled or sick children. Funding can go towards services such as specialist surgery, treatment, therapy, equipment and home modifications. To apply, please phone or email the charity with details of your fundraising project and they will advise on eligibility and next steps.

Tel: 01892 535525
Email: info@treeofhope.org.uk
www.treeofhope.org.uk

**Trefoil**

Provides grants for holidays or the personal development of children and young people with special needs. Guidelines and an application form are available from the charity’s website.

Tel: 0131 220 3249
Email: trefoil@wssociety.co.uk
www.trefoil.org.uk

**Variety, The Children’s Charity**

Grants ranging from £100 to £6,000 are available for disabled children and their families. Funding can be used on items like bath mats and hoists, mobility equipment, learning and communication equipment, plastic sheets and feeding tubes. For further
information contact the Grants Programme Manager on the number listed below. Full guidelines and application forms can be downloaded from the web page below.

Tel: 020 7428 8120
Email: grants@variety.org.uk
www.variety.org.uk

Whizz-Kidz

Provides mobility equipment to children and young people under 18 who have not been able to get the required equipment or funding through the NHS. You can apply online on the charity’s website – please see web address below – or phone or email them for a paper application form.

Tel: 0800 151 3350, email: kidzservices@whizz-kidz.org.uk
www.whizz-kidz.org.uk

Worthing Scope

Provides grants to people with cerebral palsy living in the Adur, Arun and Worthing area, or to children receiving services from the Children’s Centre at Worthing Hospital. Grants are considered for items/services which will have a demonstrable and positive effect on the quality of life of the person with cerebral palsy and/or their immediate family members.

The purpose for which the grant is to be used must not be something that should be provided for by statutory agencies, or fall within the remit of other funding bodies. Full criteria and application forms are available on the website.

Tel: 01903 821437 (community liaison worker),
Email: admin@worthingscope.org.uk
www.worthingscope.org.uk

Other Sources of Support

Lion’s Clubs, Masonic Lodges, Rotary Clubs, the Round Table and Soroptomists are known to be active in their local communities supporting individuals and families in need. You can find the local branches of any of the societies using the following links:

http://lionsclubs.co/Public/
www.rotarygbi.org
www.roundtable.co.uk
http://sigbi.org/
http://sussexmasons.org.uk

We would also recommend using the Turn2us website, which provides an online directory of grants and financial support:

www.turn2us.org.uk
The following companies and private practitioners have paid a fee for inclusion in this edition of *Making Sense of it All*. Therefore the list is not exhaustive. We hope to include more companies and private practitioners in future editions of the guide.

If you are a private practitioner or service provider in West Sussex and you would like to have a listing in the Business directory for future editions of *Making Sense of it All*, and/or *Making Sense of Adult Life*, please contact our project manager, Brian O’Hagan by emailing: brian@reachingfamilies.org.uk.

**Alfa Taxi Group**

Accessible taxi and mini bus service in Chichester and West Sussex surrounding areas. We also have a number of trained escorts. All drivers and escorts are DBS checked. We are always looking for more drivers and escorts to join our well-established company.

Tel: 01243 673923
Mob: 07888 239287
Email: alfataxis@live.co.uk

**Autism Parent Empower**

Autism Parent Empower provides Early Intervention programmes for children, parents and families living with autism. The flagship course is focused on improving behaviour, nutrition and personal empowerment.

Tel: 07931 219555, email: info@autismparentempower.org
www.autismparentempower.org

**Behaviour Advice**

Behaviour Advice is a training and consultancy service covering all aspects of educational inclusion, particularly relating to social, emotional, behavioural difficulties and wellbeing.

25 Frenches Mead
Billingshurst, RH14 9LE
Tel: 01403 780627

Email: info@behaviouradvice.co.uk
www.behaviouradvice.co.uk

**Counselling and Autism Spectrum Support (CASS)**

Social enterprise specialising in supporting people with autism and their families, in and around Sussex.
CASS - Counselling and Autism Spectrum Support
First Floor, 36 Blatchington Road
Hove, BN3 3YN
Tel 07769 218986

Clare Rader

Children’s Therapy is an independent occupational therapy practice based in Sussex offering high quality interventions to children, families and schools in Sussex, Hampshire and Surrey.

Phone: 07770 110833
Fax: 01243 914915
Email: office@childrenstherapy.co.uk
www.childrenstherapy.co.uk

Debbie Smart, Independent Speech & Language Therapist

Specialising with children and families needing support and therapy for a wide range of needs. Training can be provided for a range of settings upon request.

Email: debbiesmart2001@yahoo.co.uk

Gemma Sharp

Inclusive communication therapy: 1:1 fun sessions, focusing on developing communication and motor skills using makaton, PECS, intensive interaction, communication aids, Jump Ahead and rebound therapy.

Tel: 07876 032258
Email: gemmasharp77@gmail.com

Get Mindful

Get Mindful specialising in mindfulness and resilience coaching to help manage stress & emotional wellbeing.

Tel: 07999 925155
Email: Shirley@getmindful.co.uk

Jigsaw Occupational Therapy

An independent, family-run, specialist provider of Sensory Integration Occupational Therapy for children and young people. Our dedicated centre is the first and only one of its kind in Sussex. We can provide assessments and therapy sessions, in addition to delivering training workshops.

Lyes Farm Offices
Cuckfield Road
Burgess Hill
West Sussex
RH15 8RG

Tel: 01444 616162
Email: info@jigsaw-ot.co.uk
www.jigsaw-ot.co.uk
Miss Alignment

A qualified personal trainer with a specialism in movement and adapting exercise for people with a disability. I am passionate about my clients and achieving their goals and improving their wellbeing and quality of life.

Tel: 07799 707483
www.missalignment.co.uk

Patricia Broughton, Independent Speech and Language Therapist

Experienced Independent Speech and Language Therapist providing assessment, therapy, training, advice for the benefit of children and young people with speech, language or communication needs.

Tel: 01903 530816
www.easytalk2me.com

Renaissance Legal

Renaissance Legal is a law firm specialising in Wills, Trusts, Powers of Attorney and Court of Protection applications for families and carers of disabled children.

Tower Point
44 North Road
Brighton, BN1 1YR

Tel: 01273 610611, email: k.miller@renaissancelegal.co.uk
www.renaissancelegal.co.uk

Samantha Parrott

Listening, understanding and working with the parents and carers of children with special needs is a focus for my therapy practice. Talking it through helps.

Tel: 07967 092220, email: counselling@counsellinginhove.co.uk
www.counsellinginhove.co.uk

Sarah Squires

Qualified and highly experienced teacher specialising in providing private 1:1 or small group tuition for children and young people with SEND. Subjects covered include literacy, numeracy and creative subjects such as music and drama.

Tel: 07926 621503
Email: sarahc501@hotmail.com

Sophie Spearman
Infinity SEN Solutions

A personally tailored advocacy and consultancy service. Support at meetings, communication with relevant professionals including schools and Local Authorities, EHCP
advice, appeal management and representation at Tribunal.

76 Cranworth Road
Worthing
BN11 2JF

Tel: 07879 660410
Email: sophie@infinitysen.co.uk
www.infinitysen.co.uk

**Square One Attachment**

Individualised support or staff training on supporting children in schools experiencing attachment difficulties, offering simple, practical ideas to help these children access education successfully.

Tel: 07840 846063, email:
info@squareoneattachment.co.uk
www.squareoneattachment.co.uk

**Sussex Music Workshops**

Individual & group lessons, music therapy, and workshops including home visits. I have extensive experience of working with children with SEND and have seen first hand the benefits they get from learning a musical instrument.

Tel: 07771 880482. email:
Daniel@sussexmusicworkshops.co.uk
www.sussexmusicworkshops.co.uk
Introduction

This jargon buster is a collection of words, acronyms and phrases that may be new to you but are frequently used in health, social care and education. Although our jargon buster cannot be completely comprehensive, we hope that it will help you to understand some of the terminology that is most commonly used by professionals.

For further information about specific conditions and common issues, please refer to our fact sheets, which are free to download from our website: www.reachingfamilies.org.uk/factsheets.htm.

AAC (Augmentative and Alternative Communication) – various methods of communication which support or replace the spoken word to allow someone to communicate as effectively as possible. Methods vary from low-tech picture cards to high-tech electronic speech generating devices.

ABI (Acquired Brain Injury) – medical term referring to an injury to the brain occurring after birth.

Academy – a state-funded school that is self-governing and gets its funding direct from central government, not the local authority, giving it more freedom over its budget, how it structures the school day, and so on.

Access to Work – a grant providing practical support to enable disabled people to start work and/or stay in work. Support can include help with transport costs, equipment needed for the workplace, a communicator at interviews or a support worker to help you in the workplace.

Acupuncture – complementary or alternative form of therapy in which fine needles are inserted into various points on the body to help treat a wide range of health conditions.

Acute – describes the rapid onset of an illness. Also refers to an illness that is short in duration but progresses rapidly.

ADL (Activities for Daily Living) – everyday tasks like eating, bathing, dressing, moving around and so on.

Advice – term to describe reports provided by both parents and professionals as part of the process of an Education Health and Care (EHC) Needs Assessment.
Advocacy – independent support representing and acting on behalf of an individual, family or group. Often used to support people with learning disabilities or other SEND.

AFO (Ankle Foot Orthosis) – a splint worn on the lower leg and used to support, straighten muscles and correct their function.

Ambulatory – medical term relating to the ability to walk.

Annual Review – progress meeting between teachers, parents and children where the child an Education Health and Care Plan (or a Statement of SEN).

Appointee – a person who acts on behalf of another to manage their benefits. For example, a parent, friend, or professional who acts on behalf of someone claiming Disability Living Allowance.

AT (Assistive Technology) – a system or device designed to enable greater independence for disabled people – for example, specialist computers and software.

Audiologist or Clinical Scientist (Audiology): clinicians who provide assessment, diagnosis and rehabilitation of hearing and balance problems. This includes interventions such as hearing aids which can reduce the barriers to communication created by hearing loss.

BESD (Behavioural, Emotional and Social Difficulties) – an umbrella term for a range of difficulties with emotional regulation, social interaction and/or mental health problems, often including challenging behaviour. The term is interchangeable with SEMHD.

Blue Badge – parking permit that allows people with severe mobility problems to park nearer to their destination. For further information search for blue badge at: www.westsussex.gov.uk

Bobath Therapy – intensive but fun combination of physiotherapy, occupational therapy and speech and language therapy for children with cerebral palsy. Aims to maximise the child’s ability to move, sit, communicate and function as well as possible.

Botox (Botulinum Toxin A) – a powerful toxin which, in small doses, is used to provide safe and effective relief from tight muscles. Commonly used in the treatment of cerebral palsy and dystonia.
BSL (British Sign Language) – a visual form of communication using hands, facial expression and body language; mainly used by people who are deaf or hearing impaired. BSL is a fully recognised language and is independent of spoken English.

CAF (Contact a Family) – national charity providing information, advice and support to parents, carers, and families of children with special needs, disabilities or medical conditions. Their website provides a wealth of information for families, including an A-Z directory of a wide range of illnesses and conditions.

CAMHS (Children and Adolescent Mental Health Service) – mental health support for children, young people under 18 and their families.

Care Package – the services and support provided following an 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 £116 per week (after tax and care costs).

Carer’s Needs Assessment – an evaluation of a carer’s needs, which is carried out by social care to decide what help and support is they need.

CBT (Cognitive Behavioural Therapy) – talking 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 Development Centre (CDC) – multi-purpose clinic housing various children’s health professionals including paediatricians, physiotherapists, occupational therapists, and speech and language therapists.

Children’s Community Nursing Team – trained nurses who provide care to children outside of hospital to enable them to stay at home, school or in another community setting.

Child Tax Credits – system of payments from the government to families responsible for at least one child. How much you will receive depends on a number of factors, including how many children live with you, whether you work and for how many hours, how much you earn, if you pay for childcare and if your child is disabled.

Chronic – describes an illness or condition that lasts a long time.
**Circle of Support (or Circle of Friends)** – informal group of people (usually family, friends and other community members) who meet on a regular basis to help somebody accomplish their personal goals in life. Sometimes used in supporting people with SEND.

**Clinical Child Psychologist** – a healthcare professional who assesses, diagnoses and treats children and young people with mental health issues. May also offer counselling for families in difficulty.

**Cognitive Development** – refers to the way in which a child learns to process information, learns language, and skills in perception, problem solving and so on.

**Community Dentist** – specialist dental service, to which people with SEND and other difficulties can be referred if required.

**Community Equipment** – term used to describe equipment to aid daily living including: wheelchairs; hoists; lifts; beds; eating utensils; raised toilet seats; grab-rails and so on.

**Community Paediatrician/Community Child Health Doctor** – doctor who specialises in the health and development of children. Works in Child Development Centres (CDCs), child health clinics or in schools.

**Conductive Education** – method of teaching children with motor disorders such as cerebral palsy, which focuses on the whole child and seeks to maximise their independence and mobility, increase their self-esteem and social interaction.

**Congenital** – relating to conditions that are present at birth.

**Consultant in Rehabilitation Medicine** – specialist doctor who often leads a multi-disciplinary team to help people with complex disabilities. They work on treating and preventing symptoms and complications, and have specialist expertise in areas such as wheelchairs, orthotics and assistive technology.

**Continence Team** – 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.
Continuing Care – fully funded health care provided in the community to a child or adult with a disability, injury or illness over an extended period of time.

Co-production – when everyone involved with the child or young person, including parents and carers, works together to agree outcomes and produce recommendations, plans, actions and materials as a collective.

CT (computerised tomography) or CAT (computerised axial tomography) scan – scan using X-rays and a computer to provide detailed images of the inside of the body. Used in the diagnosis of many different health conditions.

Developmental Delay – term which refers to a child meeting milestones much later than expected for their age range in one or more of the following areas: physical; personal and social skills; thinking and learning; speech and communication.

Developmental Disorder – umbrella term to describe a number of conditions that affect neurological development, such as autism, Asperger’s syndrome, global developmental delay and learning disabilities.

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. Includes modifications to the National Curriculum, if appropriate.

Direct Payments – funding paid directly to disabled people who have been allocated a Personal Budget so that they or their carer can choose and organise their own care or services.

Disability Equality Duty – a legal requirement of all public sector organisations such as schools, hospitals and the NHS, 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.
Disagreement Resolution – an arrangement for resolving disputes between parents of children with SEND and their local authority, school, health or care agency. Must include an independent facilitator.

Disapplication – removal or lifting of any element of the National Curriculum for a child with SEND.

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 is 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.

DSA (Disabled Students’ Allowance) – additional financial help over and above the standard student financial package for disabled people who want to study in higher education.

Dysphagia – medical term referring to a difficulty with swallowing.

Early Bird – training programme from the National Autistic Society designed to help parents of children with autism to better understand the condition and improve their child’s behaviour and communication.

Early Help Assessment – an assessment of a child and their family designed to identify needs at an early stage and enable suitable interventions to be put in place to support the family via an Early Help Plan.

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.

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.

EHC Needs Assessment – the process by which children and young people with SEND are assessed for an Education, Health and Care Plan.
EHC Plan or EHCP (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. An EHC Plan covers the health and social care needs of a child as well as education. 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 sector organisations to actively promote equality of opportunity for disabled people.

ESA (Employment and Support Allowance) – a government benefit providing financial support if you are unable to work or personalised help so that you can work if you are able to. Includes an assessment carried out by a healthcare professional of a person’s capability for work.

EYFS (Early Years Foundation Stage) – government framework for the learning and development of children aged from birth to five years. All providers of education and care of young children must follow the requirements of the framework.

EYPARM (Early Years Planning and Review Meeting) – joint planning meeting involving education, health and social care professionals to discuss and plan support for a pre-school child who may have SEND.

Fine Motor Skills – use of smaller muscle groups and hand-eye co-ordination to carry out precise tasks like writing, picking up objects, fastening clothes and so on.

Fully Accessible Toilet – any toilet equipped with an adult-sized changing bench, a hoist and enough space for two carers to see to the toileting/changing needs of a disabled person for whom a standard disabled toilet is not an option.

Gait – term to describe the way in which a person walks.

Gaiters – type of splint used to straighten elbows or knees.

Gastrostomy – an artificial surgical opening in the stomach to aid feeding and nutritional support.
GDD (Global Developmental Delay) – term used when a child has not reached two or more age appropriate milestones in all of these areas of development: physical; personal and social skills; thinking and learning; speech and communication.

GP (General Practitioner) – a family doctor based at the local doctors’ surgery.

Graduated Approach – approach to working with children with special educational needs in early years settings, schools and colleges, which emphasises gradually bringing in additional support and expertise to support a child’s learning and development, using an ‘assess, plan, do, review’ model.

Gross Motor Skills – use of the large muscles in the body that enable standing, walking, lifting, and sitting.

Health Visitors – qualified nurses who work mainly with families who have children under five. Sometimes keep in touch with families of older children with SEND.

Homeopathy – alternative form of medicine where a patient is given highly diluted substances with the aim of ‘triggering the body’s natural system of healing’.

Hospice – providers of specialist care to children who have life-limiting or life-threatening illnesses.

Hypertonia – medical term to describe increased muscle tone and the reduced ability of a muscle to stretch.

Hypotonia – medical term to describe decreased muscle tone often involving low muscle strength.

Hypoxia – medical term to describe when a person or a region of the body is deprived of an adequate oxygen supply.

Inclusion – commonly used term in education to describe the principle by which children with SEND attend school and fully participate in the curriculum alongside typical pupils.

InCo (Inclusion Co-ordinator) – another name used to describe the role of the SENCO (Special Educational Needs Co-ordinator).

Independent Supporter – helps parents of children with SEND when transferring from a Statement of SEN to an EHC Plan and those applying for an EHC Plan.

Kaye Walker – walking frame for children with mobility problems.
Key Stages – the National Curriculum is broken down into four phases known as key stages. They are based on age groups: Key Stage 1 (five to seven); Key Stage 2 (seven to 11); Key Stage 3 (11 to 14); Key Stage 4 (14 to 16).

Key Worker – education, 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.

LDD (Learning Difficulties and Disabilities) – a term sometimes used by schools and colleges to refer to all learning differences which require special educational support.

LD (Learning Disability) – general term to describe various intellectual and social impairments present from childhood that prevent or hinder a person understanding, learning or remembering new subjects or skills. Also known as an intellectual disability or cognitive disability.

LSA (Learning Support Assistant) – widely used term to describe a member of school staff who provides individual or small group support in the classroom.

Mainstream School – ordinary or community school managed by the local authority.

Makaton – a communication system that involves the combined use of manual signs and speech. Useful for children with learning disabilities and speech/language difficulties to help them understand and communicate.

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 EHC Plans before considering tribunal.

Medical Model of Disability – a view of disability in which people are defined by their impairments. Emphasises the problem, not the person, and the need for medical intervention or correction of the problem. Often used in comparison with the social model of disability (see page 255).

Mild Learning Disability – term used to describe the cognitive ability and functioning of a person with an IQ of 50 to 70. Someone with this diagnosis is usually able to hold a conversation and communicate most of their needs and wishes. They may need some support to understand abstract or complex ideas. People are often independent in caring for themselves and doing many everyday tasks. They usually have some basic reading and writing skills. People with a mild learning disability often go undiagnosed.
MLD (Moderate Learning Disability) – term used to describe the cognitive ability and functioning of a person with an IQ score of 35 to 50. Characterised by the person having problems acquiring skills in literacy and language. Often there are associated problems with speech and communication, and social skills.

MMR (Measles, Mumps and Rubella) – combined vaccination that protects against the above diseases. Has been incorrectly suggested as a cause of autism.

MRI (Magnetic Resonance Imaging) scan – type of scan using powerful magnetic fields and radio waves to produce detailed images of the inside of the body. Used to diagnose health conditions affecting bodily organs, tissue and bones.

MSI (Multi-Sensory Impairment) – refers to a combination of sight and hearing difficulties.

Multi-disciplinary – a group of professionals from different specialities who assess and plan support for a child or adult.

Muscle Tone – refers to the amount of tension or resistance to movement in a muscle. Involved in movement, posture and so on.

Music Therapy – form of therapy often used to help communicate and build relationships with people through playing, singing and listening to music.

National Curriculum – covers the learning of all children aged five to 16 years in state schools in England. Includes 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.

NG (Nasogastric) Tube – plastic tube inserted via the nose into the stomach to aid feeding.

NT (Neurotypical) – shorthand for ‘neurologically typical’, often used for people who do not have an autistic spectrum condition.

OFSTED (Office for Standards in Education, Children’s Services and Skills) – inspects and regulates services that care for children and young people, and services providing education and skills for learners of all ages. Provides online reports on childcare providers and schools.
**Ophthalmologist** – medically trained doctor with specialist skills in the diagnosis, treatment and prevention of eye conditions.

**Optometrist** – healthcare professional who performs eye tests and prescribes corrective lenses or glasses to those who need them.

**Orthoptist** – healthcare professional who investigates, diagnoses and treats difficulties with binocular vision and problems with eye movement. This includes double vision, reduced vision and eye misalignments (squints).

**Orthotist** – healthcare professional who assesses individuals for and designs specialist braces, splints and footwear to support weak joints or muscles.

**Osteopathy** – a way of detecting, treating and preventing health problems by moving, stretching and massaging a person’s muscles and joints.

**OT (Occupational Therapist)** – healthcare professional who works with disabled people to improve their skills in carrying out everyday activities.

**Paediatrician** – specialist doctor who manages conditions affecting babies, children and young people.

**Paediatric Liaison Health Visitors** – based at Chichester and Worthing hospitals, they are trained children’s nurses with specialist knowledge of children’s conditions. They can supply community health visitors with detailed information relating to your child’s condition.

**Palliative Care** – provision of nursing, pain management, social, psychological and spiritual support to people who are dying.

**PALS (Patient Advice and Liaison Service)** – provides information and advice on the NHS and investigates complaints made by patients.

**Paraplegia** – impairment in motor or sensory functions in the lower half of the body resulting in complete or partial paralysis in both legs. Usually due to injury or disease of the spinal cord.

**Parent Carer** – term used to describe the dual roles of parents of children, young people and adults with SEND. Helpful in recognising that these parents have caring responsibilities above and beyond other parents.
Parent Participation – the active involvement of parent carers in the planning of services for families of children and young people with SEND.

Pastoral Care – provision by schools that focuses on the personal, social and emotional needs of pupils.

Pastoral Support Plan – school strategy to help children improve their social, emotional and behavioural skills. Often used with children at risk of exclusion.

PECS (Picture Exchange Communication System) – picture-based system commonly used by pre-verbal or non-verbal children on the autistic spectrum or with a learning disability.

PEG (Percutaneous Endoscopic Gastrostomy) Feeding or G Tube – a method of feeding liquid food to a person whose oral intake is not adequate due to swallowing difficulties or sedation. The PEG tube is passed into the person’s stomach through the abdominal wall in a hospital procedure.

Personal Budget – an amount of money identified by the local authority to deliver care and support. Allows disabled people and their carers flexibility to choose which services and support to use.

Personalisation – the provision of care and support based on the individual’s 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 support they need to achieve their goals.

Physiotherapist – healthcare professional who helps people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice.

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.

Play Therapy – the use of play to help children understand difficult life experiences and feelings in order to reduce anxiety, improve self-esteem and better manage their emotions and behaviour.

PMLD (Profound and Multiple Learning Disabilities) – refers to the cognitive and physical ability and functioning of people with more than one disability including
a profound learning disability. People with PMLD have an IQ of less than 20, very high care needs and experience considerable difficulty communicating. They may also have visual, hearing or movement impairments, complex health needs, epilepsy or autism.

**Portage** – a home-visiting educational service for pre-school children with SEND and their families. Owes its name to the town in Wisconsin, USA, where it was first developed.

**Prognosis** – medical term to describe the likely progress and outcome of an illness, condition or disability.

**Progressive** – term used to refer to an illness or condition that generally gets worse over time.

**Provision Map** – a brief document giving a view of how a school will support a child with additional needs.

**PRU (Pupil Referral Unit)** – also known as ‘alternative provision’, these are specialist schools run by local authorities for children who have been excluded, have health issues or are otherwise unable to attend a mainstream or special school.

**Psychiatrist** – doctor who specialises in diagnosing and treating people with mental health issues.

**Quadriplegia** – refers to complete or partial paralysis of all four limbs and torso. Also known as Tetraplegia.

**RADAR Key** – a key which opens most locked disabled and fully accessible toilets. Available from your district or borough council, mostly free of charge.

**Reconsideration** – the reassessment of an application for DLA or PIP that was initially turned down. Over 50 per cent of decisions are overturned on reconsideration.

**Respite** – a break from caring for someone with an illness or disability.

**Revision** – a new decision by the DWP on a DLA or PIP application. Replaces the old decision and takes effect from when it was originally made.

**SALT (Speech and Language Therapist)** – healthcare professional who diagnoses and treats people with speech, language, communication and understanding difficulties, plus individuals with swallowing and feeding problems.

**Scoliosis** – a sideways twisting and curvature of the spine that can also pull the ribcage out of position.
SEMH (Social, Emotional and Mental Health) Needs – an umbrella term for a wide range of social and emotional difficulties, including becoming withdrawn or isolated, or displaying challenging behaviour. These behaviours could be as a result of underlying mental health issues or other conditions such as ADD, ADHD or attachment disorder. Used to be known as BESD.

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.

SENCo (Special Educational Needs Co-ordinator) – member of staff in schools who is responsible for the co-ordination of special educational needs provision to ensure that pupils with SEND are supported.

SEND Code of Practice – statutory government guidance that explains the duties of local authorities, schools and other organisations that work with and support children and young people with SEND. Covers issues like EHC Needs Assessments, EHC Plans, Annual Reviews, inclusion, the Local Offer, Personal Budgets and Direct Payments.

SEND IAS (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 education, health and social care.

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.

Sensory Integration – the process by which the brain receives, processes and uses information from the five senses (sight, hearing, touch, smell and taste), the sense of balance and of knowing one’s position in space and in relation to others (proprioception).

Sensory Integration Therapy - therapy to help children who have sensory integration disorder or sensory processing disorder. The aim is to encourage the brain to change its response to sensory stimuli. A child’s individual needs will be assessed before a programme of therapy is designed for them.
SEN Support – additional support for children and young people with SEND that is made from a nursery, school or further education college’s own resources. If a child has more complex needs they may need an EHC Plan.

Severely Sight Impaired – term used to describe blindness.

Short Break – leisure and social activities outside the school day for children and young people with SEND, which also give parents and carers a break from their caring role.

Sight Impaired – term used to describe partial sight loss.

Signalong – a system of communication which uses signs based on British Sign Language and the simultaneous use of the spoken word.

SLCN (Speech, Language and Communication Needs) – umbrella term referring to difficulties with listening and understanding, or with talking or both.

SLD (Severe Learning Disability) – term to describe the cognitive ability and functioning of people who have an IQ score of 20-35. Characterised by substantial difficulty in acquiring literacy and language skills and often, associated problems with mobility, co-ordination, communication, perception and acquiring self-help skills.

Social Model of Disability – view of disability that states it is created by society as a result of physical and cultural barriers and attitudes which lead to discrimination and exclusion. Used in contrast to the medical model of disability.

Spasticity – medical term for muscle stiffness.

SPD (Sensory Processing Disorder) – sometimes called sensory integration disorder, this is a condition where the brain struggles to interpret information from the different senses.

Special School – a school that specialises in education provision for children with SEND.

Spider Therapy – form of treatment for people with cerebral palsy that involves attaching a number of elastic cords to the person’s body enabling them to move independently but in a way that controls movement and strengthens parts of the body affected by their condition.
Spinal Jacket – specially designed brace used to support and correct the spine. Sometimes known as a TLSO (Thoracolumbo Sacral Orthosis).

SpLD (Specific Learning Difficulty) – a difficulty with certain aspects of learning. The most common SpLDs are dyslexia, dyscalculia, dyspraxia and dysgraphia.

Statement of Special Educational Needs – former document written by local authorities which sets out a child’s special educational needs and how they should be helped, what type of school they should attend, what non-educational support they might need and how this will be met. Statements are being replaced by EHC Plans.

Supercession – a new decision by the DWP on an application for DLA or PIP. Comes into effect from that moment on.

Switch Access – technological device used to access computers for people with severe physical disabilities. The switch replaces the need for a mouse or keyboard.

TA (Teaching Assistant) – a member of school staff who provides individual or small group support in the classroom. Also known as a Learning Support Assistant or a Special Support Assistant.

TAF (Team around the Family) – team of professionals from various backgrounds and services working together to provide joined-up support for a child or young person and their family.

Temporary Disapplication – removal of those parts of the National Curriculum where it is impossible or inappropriate for the child to participate.

Trauma – a serious injury or shock to the body.

Triad of Impairments – term that describes the impairment of social interaction, social communication and social imagination pervasive in all autistic spectrum conditions.

Triage – process by which a patient’s treatment is prioritised based on the severity of their condition and the need for immediate medical attention.

Universal Credit - a monthly government benefit that replaces some other benefits. You may be able to claim Universal Credit if you’re on a low income or out of
work. How much you’ll get depends on your circumstances, including your income and how many children you have.

**VOCA (Voice Output Communication Aid)** – or Speech Generating Device, an electronic device which allows people who are unable to use natural speech to generate printed or spoken text.

**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 being in receipt of the middle or higher rate care component of DLA.

**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. Used in the assessment of eligibility for Employment and Support Allowance.

**Working Tax Credit** – a system of payments from the government to people who work 16 hours or more per week and are paid for that work.
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