2025/26

South East Guide to SEND

for Parent Carers of Children and Young People with
Special Educational Needs and Disabilities (SEND)
from birth to 25 years

Published by
my family our needs

www.myfamilyourneeds.co.uk

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Contents

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Recite me

This guide is available electronically at **www.myfamilyourneeds.co.uk/** The e-book is also Recite Me compatible for those requiring information in the spoken word.

Contents continued

Look out for the magnifying glass next to abbreviations. The full wording and meanings can be found in the glossary.

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Introduction and Welcome from *My Family, Our Needs*

Welcome to this independent South East Guide for Parent Carers of Children and Young People with Special Educational Needs and Disabilities (SEND), from birth to 25 years. Created by *My Family, Our Needs*, this guide brings together useful information to help families know where to start.

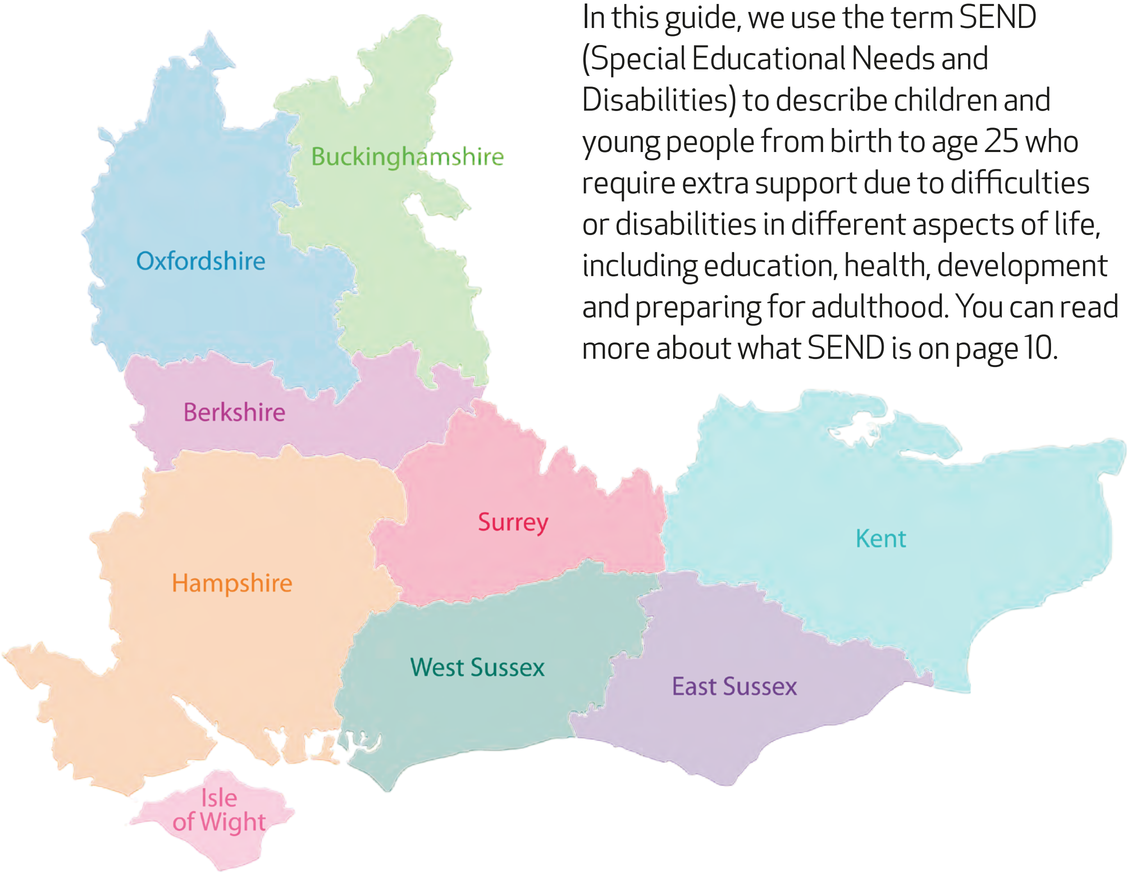
Inside, we hope you'll find clear answers to the questions parents tell us matter most. Our aim is to help you navigate support with confidence and make finding the right information quicker and less overwhelming.

This guide covers all nine counties in the South East, offering both general SEND guidance and county-specific details.

We also signpost to further information, with direct website links and contact details where available. We hope this guide will make the SEND journey clearer and more manageable, so you feel better equipped to support your child.

Visit the *My Family, Our Needs* website, where you'll find all the information in this guide and additional resources to support your family's SEND journey.

In this guide, we use the term SEND (Special Educational Needs and Disabilities) to describe children and young people from birth to age 25 who require extra support due to difficulties or disabilities in different aspects of life, including education, health, development and preparing for adulthood. You can read more about what SEND is on page 10.



Early Years

'Early Years' refers to the early education of children from birth to the age of five. This can be delivered by nurseries, childminders or pre-schools. Early education contributes to a child's independence, learning and social skills.

The Early Years Foundation Stage (EYFS) framework sets the national standards for care, learning and development of children from birth to age five. It ensures children are safe, supported and learning well in key areas like language, physical development and social skills.

All Early Years' practitioners (childminders, pre-schools, nurseries and school reception classes) must be registered with Ofsted, which inspects educational and childcare settings for quality and safety standards. For more information on the EYFS Statutory Framework, visit **www.gov.uk/early-years-foundation-stage**

The Two-Year Integrated Review

A key part of the EYFS is the Two-Year Progress Check, which reviews your child's development between two and three years old. In many areas, this is combined with the health visits check to form the Integrated Two-Year Review. For children with SEND, this helps identify support needs early and ensures a joint approach between education and health services. Read more on health services on page 65.

This integrated review is implemented across all nine areas of the South East. The process can vary between counties in terms of who carries out the reviews and the stages at which a full picture of your child's development is reached. For specific details in your area, visit your local authority's website and search 'Two-Year Progress Check'.

All registered specialists will have an identified Special Educational Needs and Disabilities Co-ordinator (SENDCO). If a case is considered complex (medical or educational) then referrals may be made to wider services like health and social care settings as needed.

Diagnosis

A diagnosis refers to the identification of a condition that impacts on an individual's ability to learn, communicate, comprehend, see, hear or physically function. Diagnoses are typically made by an education or medical professional, such as your child's GP or health visitor, and involve assessing your child's developmental and functional abilities.

It can involve identifying a range of conditions, including learning disabilities and neurodevelopmental disorders, each with varying impacts on your child's life.

If your child's abilities are impacted by any condition, you can speak to their GP or health visitor in the first instance. They can assess your child and refer you to specialists if needed who may provide a diagnosis.

The diagnosis process can involve a combination of clinical history, physical exams and various assessments, including standardised tests and evaluations to determine limitations in adaptive behaviour.

The NHS Right to Choose (RTC) pathway in England allows patients to choose their healthcare provider for certain NHS-funded services. If your child is referred by their GP for an autism or Attention Deficit Hyperactive Disorder (ADHD) assessment, you have the right to choose which NHS provider will carry out the assessment. You should research providers and tell your GP your preferred provider. Most providers have a template form or letter on their website you can fill out and give to your GP. The RTC pathway typically leads to faster access, reducing your wait time for an assessment.

A diagnosis can help you and your child access appropriate support services, education plans and therapies to help your child thrive.

If your child is not diagnosed, you can still seek support from professionals, including your GP, health visitor and other relevant specialists to address specific needs or concerns. A child does not need a formal diagnosis or named condition to be assessed for SEND.

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Special Educational Needs and Disabilities (SEND)

SEND refers to a broad range of needs that require special educational provision, meaning extra support is required to learn. Services for SEND are often grouped together. However, there is a difference between the two:

- A child has a **special educational need** if they have a difficulty or disability that requires special educational provision to be made for them.
- A child has a **learning difficulty or disability** if they have significantly greater difficulty in learning than the majority of others of their age or they have a disability that prevents or hinders their ability to access educational facilities that are provided for children of their age in a mainstream setting.

Likewise, a diagnosis of a condition does not automatically mean a child has SEND and needs to be assessed and diagnosed individually. A child can have a disability such as a mild visual impairment without needing special accommodations at school.

How can I access SEND provision for my child?

If you feel your child requires SEND provision, you should start by talking to your child's school, SENDCO or teacher about your concerns.

There are four key areas they will consider:

- **Communication and interaction** – children with speech, language and communication needs may find it difficult to understand others or to communicate with them effectively. They may also have difficulties with social communication like those with autism.
- **Cognition and learning** – children may learn at a slower pace than others and have difficulties with understanding, organisation and memory skills, among other things. This covers a broad range of – and multiple – learning difficulties, from moderate to severe to profound. This includes specific learning difficulties like dyslexia, dyspraxia, dysgraphia and dyscalculia.
- **Social, emotional and mental health difficulties** – children may show difficulty managing their relationships with others and may be withdrawn or display challenging behaviour. They may have underlying mental health conditions like anxiety or depression and they may self-harm or have eating disorders. Some children may have ADHD.
- **Sensory or physical needs** – children may have sensory impairments such as difficulties with their visual impairment, hearing impairment or

a multi-sensory impairment, which require ongoing support or equipment. Physical needs can also refer to those with physical disabilities where they impact on access to learning.

The school should put provision in place according to the identified need.

If, in the process of assessing what support is required for your child, the school feels external professional support is needed, they can make a referral to the relevant service. You can also self-refer to a healthcare professional like your GP or paediatrician for their input. When children are assessed, professionals can identify what their needs are and recommend what provision they will require. Read more on professionals on page 15 and 68.

Your child may not always be given a diagnosis by professionals but if they are, this can include:

- Autism.
- Learning difficulties like dyslexia, dyspraxia and dyscalculia.
- ADHD.
- Medical needs like epilepsy and cerebral palsy.
- Other mental health issues like anxiety, Obsessive-Compulsive Disorder (OCD 🔍) and bipolar disorder.

Targeted Support (Early Help)

Targeted Support (previously Early Help) is the support given to children, young people and their families who have needs that are not met by universal services. Universal services are services that are available to everyone, like health and education.

When a family has more needs, Targeted Support ensures they have access to the support they require at the earliest possible stage. Targeted Support access may need a completed Early Help Assessment (EHA), although this depends on your area, which can be offered from infancy up to age 18. While Early Help and EHAs are not solely associated with SEND support, they may progress into such help if your child's needs are significant enough.

What is an Early Help Assessment (EHA) and how can you request one?

An Early Help Assessment (EHA) is a process used to identify the needs and challenges a child or young person may be experiencing across areas like health, education and family life, including physical, cognitive, behavioural and social-emotional development.

The EHA is also used to access other forms of support, such as neurodevelopmental assessments for things like autism or ADHD, and can help facilitate referral to appropriate specialist teams to ensure your child receives the right support at the right time. Read more on assessments on page 8.

Accessing an EHA varies slightly by area and may be structured differently in terms of how the support is given and who can refer your child. Typically, you can self-refer directly to your local authority through its website or by phone. You can also contact a professional who may already be working with your family, like a health visitor, GP or teacher who can guide you through the process of requesting an EHA and may be able to lead one for you.

The assessment is a collaborative process usually completed by a lead professional already working with your family, with input from your family and relevant professionals like teachers, social workers or healthcare providers. They will discuss your family's situation, identify needs and develop a plan to address those needs.

For specific information on Early Help and requesting an EHA in your area, visit your local authority's Local Offer (details on page 96) and search 'Early Help'.

What is an Early Help Plan?

Once the EHA is completed, an Early Help Plan is created by the relevant professional, detailing the support needed, services to be provided and the actions to be taken. The focus of an Early Help Plan is to provide targeted support for families to address challenges early on. This is to stop your child's needs from becoming so great that they need more specialist support later on.

The plan typically includes an assessment of your family's strengths and needs, followed by tailored action points to support those needs. It could include home-visiting programmes, parenting support, access to resources, school-based programmes, mentoring, relationship support for you as parents or specialised help like speech therapy. Like the assessment, the plan is developed collaboratively with your family.

The plan should be regularly reviewed to monitor progress, identify any new needs or concerns and make adjustments as necessary. The identified lead professional will co-ordinate the work of other services and ensure the plan is carried out.

An Early Help Plan can evolve into an Education, Health and Care Plan (EHCP) later in life if the needs outlined are significant enough to require ongoing specialist support and provision. Read more on EHCPs on page 26.

Early Support Pathway

An Early Support Pathway provides a co-ordinated care approach to children from birth to five years old with complex health, education or care needs. These children will require considerable ongoing support from across education, health and care. This includes children who have:

- Great difficulty with communication.
- Sensory or physical difficulties.
- Complex health needs.

With parental consent, a professional can refer a child to Early Support after completing an EHA.

All counties in the South East have an established Early Support Pathway. Some counties differ in their structure; for example, Oxfordshire requires a Single Point of Request for Involvement form, while East Sussex provides a Pre-Autism Pathway. While all areas offer a similar level of support, check your local authority's Local Offer (details on page 96).

Early childhood specialists

Early childhood specialists support the development of young children by providing guidance, advice and resources to Early Years' settings, helping ensure that children receive the appropriate care, support and educational opportunities.

The types of early childhood specialists and the services they offer can vary depending on your local area. A practitioner who might require support to meet the needs of a child in their Early Years' setting can request support from the early childhood specialists, provided they have consent from you as parents. The team may also offer support to reception class staff who are not experienced in supporting children at a significantly lower stage of development. For example, in Surrey, Bright Horizons UK employs an Early Childhood Specialist to provide pedagogical support to nursery teams.

Early Years and educational workers who may be involved in your child's life:

Early Identification Officer

Early Identification Officers provide guidance and support to families with a young child who has complex needs. They offer support to parents in various ways, including collaboration with other partners, developmental support, transition navigation and assistance with form completion. Not every county may have an Early Identification Offer, or their title may vary. Check your local authority's Local Offer (details on page 96) to find provision in your area.

The service can support you in identifying and visiting childcare settings, arrange any specialist training that may be required to assist you in meeting your child's needs, assist you with school placement applications, and support you with the process of applying for an EHCP 🔍 where needed.

Portage service

Portage is a home-visiting educational service that supports families with pre-school children with additional needs and/or disabilities.

The service works with families in developing ways to play, learn and engage with their local community through regular home visiting to the child and their family using a model of support.

A Portage service is often managed by your local authority, which then assigns a Portage worker to eligible families who request it or are referred.

Your portage worker may then advise you on other services that they feel would be beneficial. These may include training for parents, training for settings and other services supporting children with complex needs in their early years, referrals to parent/carer groups, SEND specialist work to support children from birth to five years old who are not attending a pre-school educational setting, and support for families with their child's transition to pre-school.

The National Portage Association (NPA) provides a framework and training for Portage services.

Each county has slightly different eligibility criteria and specific forms for requesting support.

If you think your child may benefit from a Portage worker, you should contact your local authority's Portage service directly. You can find local information on the NPA website, which has details of all registered Portage services and who to contact.

The National Portage Association
www.portage.org.uk

Alternatively, check your local authority's Local Offer (details on page 96). It is important to note that not every area has a Portage service.

You can also request Portage services through your child's health visitor, GP or another healthcare professional, as well as through educational settings like nurseries or schools. These professionals can then make a referral on your behalf based on your child's specific needs.

Family Hubs

Family Hubs are local centres where you can access a wide range of support services in one place, including Early Years' support, parenting advice, health visiting, mental health resources, and advice from various educational professionals. All nine counties in the South East have one or more family hubs or equivalent services available locally. Check your local authority's website to see if there is a family hub in your area.

Barnardo's Child and Family Centres

In Hampshire, the Isle of Wight and Surrey, Child and Family Centres are run by Barnardo's and offer a variety of activities for children from birth to five years old and their parents/carers. The core purpose is to ensure that all children have the best start in life and achieve positive outcomes.

Each centre will offer different activities; however, there are things for parents and children from birth to five years old, as well as expectant mothers. Barnardo's Child and Family Centres offer a range of drop-in sessions, which may include:

- Baby Time.
- Rhyme Time.
- Sing and Sign.
- Song, Rhyme and Story Time.
- Stay and Play.

The centres also offer other groups and courses that require online booking. These may include:

- Baby massage.
- Driving Healthy Lifestyles.
- Every Child A Talker (ECAT 🔍) – Chatter Matters, Sign and Sing and Tots Talking.
- Mighty Milestones.
- Peer Early Education Partnership (PEEP 🔍) – Antenatal, Birth to Walking and Toddler to Five.
- Sensory Learners and SEND Support Group.
- Starting Solids.

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→ In each of the three counties, the Health Family Centres differ in their provision and operation.

Visit **www.barnardos.org.uk** and search '[your area] Health Family Centre'.

- **Hampshire** – Barnardo's collaborates with Southern Health NHS Foundation Trust to deliver the Hampshire Healthy Families 0–19 service.
- **Isle of Wight** – Barnardo's manages three Family Hubs located in Newport, Ryde and Sandown with additional delivery sites.
- **Surrey** – Barnardo's operates several Family Centres on behalf of Surrey County Council, including locations in Epsom & Ewell, Runnymede, Surrey Heath, Tandridge, Waverley, and Woking.

Help paying for childcare

While your children are pre-school age, you can claim funded childcare and education. To access your childcare account, visit **www.gov.uk/sign-in-childcare-account**

DISCLAIMER: The information listed below is correct at the time of publication and is subject to change. Please check **www.gov.uk/browse/childcare-parenting/childcare** for up-to-date information.

- **Tax-free childcare** – parents can get up to £2,000 a year per child to help with the cost of childcare. This goes up to £4,000 a year if your child has a disability.
- **Free childcare for children aged nine months to two years**– from September 2025, parents of children between nine months and two years of age who work at least 16 hours per week can apply for up to 30 hours of funded childcare per week, over 38 weeks, which is equivalent to 1,140 hours per funded year, eligibility dependent. You can apply from when your child is 23 weeks old and support will come into effect when your child turns nine months old.

  If you are currently claiming 15 hours of funded childcare as a working parent, you can keep claiming as normal and, if you're still eligible, it will automatically be updated to 30 hours.
- **Funded early education and childcare for families receiving additional support** – if you are on Universal Credit and earning less than £15,400 a year, or if your child has an EHCP 🔍, you could be eligible for funded education and childcare places the term after your child turns two.
- **Funded childcare for three- and four-year-olds** – all children aged three and four years of age can receive up to 570 hours of funded early education and childcare per year,

equalling 15 hours per week term time or 11 hours per week all year round.

- **Extended entitlement for working families** – children of working parents may also be entitled to an additional 570 hours per year on top of the universal entitlement, meaning these families will be able to claim up to 1,140 hours of funded early education per year, equalling up to 30 hours per week term time or 22 hours per week all year round. Visit **www.gov.uk/apply-30-hours-free-childcare**

It is important to note that eligibility depends on whether you are working, your income, your child's age and circumstances, and your immigration status. To check what is available to you, visit **www.childcarechoices.gov.uk**

PORTAGE SERVICES

The manager of our local Portage service visited us when Coraline was just two months old.

Pam brought toys for Coraline: a spongy ball, beads, dangling mirrors and a shower loofah. She explained it was all about textures and Coraline loved exploring them. Pam's knowledge and energy were infectious.

We told Pam that the appointments and liaising with healthcare professionals had begun after we brought Coraline home from the hospital, and she said, 'You might want to keep one day free where you have no healthcare appointments at all.'

Pam is another of those people whose energy rubbed off on us, who makes things happen, who creates opportunities.

She let us know that she had just the lady in mind to be our Portage worker. Teresa came fortnightly to work on developmental goals with Coraline through play. I loved it when Teresa presented me with the sheet of goals early on for us to work on with Coraline and said: 'You see this goal here, '**Have fun**!' – that's always on the sheet of goals.'

Liz Arriens-Troy is author of the memoir *Everybody Wants a Dance with Coraline* and mother to Coraline who is eight years old and has Down's syndrome.

OUR RELATIONSHIPS WITH CORALINE'S THERAPISTS

Some therapists we have for a while, some change often. We have appreciation for them all. I am always learning from them. They are kind.

When Coraline was almost four, she was on the waiting list for NHS Occupational Therapy. A friend suggested we chat to a private OT, Shelley from Hemispheres in Surrey. She gave me a free introduction chat for 20 minutes and it was like every question that had been puzzling me for ages was answered. She stood out because of her background – she worked in neurology and neurosurgery before moving into paediatrics and she specialised in neurodevelopmental and reflex integration. She explained how some of the early stages of neurodevelopment would have remained immature when Coraline was born as a result of her having Down's syndrome. For example, some reflexes develop in utero and are practised there so when a child is born these are active and this may not have happened for Coraline.

I explained that Coraline doesn't like having her face and head touched or hair brushed but she likes us stroking her foot or hand. She explained that this is because the cranial nerves that serve the face connect directly to the brainstem, making the input overwhelming, while the body has long nerves from the cortex, down the spine into the body. She suggested gentle desensitisation exercises with light touch and pressure.

She explained why Coraline doesn't like playgrounds as this is to do with her vestibular system (balance). She said that counter to the vestibular system is proprioception (awareness of body in space) and so by doing some joint compression and squeezing exercises Coraline becomes more aware of her body and less frightened of those kinds of movements.

Pretty amazing knowledge, insights and solutions!

Schools and learning

Every child deserves the same opportunity to meet their potential. For children with SEND, this means making sure they can develop skills, make friends and gain independence during the time they spend in education with support that starts in the classroom and grows with them.

School readiness

Helping your child prepare for school will build their confidence so that they start school confident, curious and ready to learn. School readiness refers to a child's ability to transition into formal education, covering not just academic skills but also social, emotional and physical development.

For children with SEND, it includes ensuring they have the skills, support and confidence needed to thrive in school. This may involve developing communication, self-regulation and motor skills, as well as access to any additional support or adjustments required to help them succeed in the school environment.

All counties in the South East have dedicated resources to ensure children with SEND are supported and ready for school. While their provisions may vary by county, most authorities offer tailored workshops, information, a readiness checklist, and advice on giving your child the best start to their school setting.

Schools' SEND support

Every child with SEND should have SEND support. This means help that is different from or additional to the support given to other children of the same age. The purpose of SEND support is to help children achieve the outcomes or learning objectives set for them by the school. The school should involve you in this process.

Every school must publish a SEND information report about the SEND provision the school makes on its own website. You can also ask your child's teacher or the school's SENDCO 🔍 for information on the SEND provision made by the school.

The school should decide if your child needs SEND support. The school should talk to you and your child about this. If a young person is 16 or older, the school should involve them directly. If you think your child may need SEND support, you should talk to your child's teacher or to the SENDCO. Read more on access to SEND provision on page 10.

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→ If you are not happy about the support your child has, you can ask to talk to the SENDCO 🔍 or Headteacher. You can also find out more about the support available to you by checking your local authority's Local Offer or contacting your local SENDIASS 🔍 (details on page 96 and 97).

When your child is identified with SEND, the school should follow the **graduated approach**, as outlined in the SEND Code of Practice applicable country-wide. It may also be called the 'Assess, Plan, Do, Review cycle'. The framework is based on the following four steps and is usually documented in a learning plan that details the needs, targets and provision in place to support your child. Every school will have their own name and acronym for the plan such as a PLP, IEP, IPP, SEP, etc.

Assess

Teaching staff should work with the SENDCO to assess your child's needs, so they can provide the right support. They should involve you in this and, where possible, seek your child's views. Sometimes schools will seek advice from a specialist teacher or a health professional. They should talk to you about this first.

Plan

If the school decides your child needs SEND support, it must tell you. The school should talk with you about the outcomes that will be set, what help will be provided and agree on a date for progress to be reviewed. This should all be set out in a learning plan. The plan describes your child's needs, the support they require, their targets, and what the school is doing to meet those needs and targets. If your child is to receive help from services outside the school, this will also be outlined in the plan.

Your child's SENDCO or teacher is responsible for managing the maintenance of the plan.

Do

Your child's class or subject teacher is usually responsible for the work that is done with your child and should work closely with any teaching assistants or specialist staff involved. The school should tell you who is responsible for the support your child receives. All those who work with your child should be made aware of their needs and support agreed.

Review

The school should review your child's plan at least three times a year. This may be incorporated into another meeting such as parents' evening or meetings that involve professionals from other services. You and your child should be involved in the review and your views should be recorded. Where possible, everyone involved in your child's education and support should take part in the review.

When reviewing the plan, your child's teacher may consider if appropriate targets have been set, whether your child met those targets, if the support was suitable and effective, if your child is making progress, and if there are any problems.

If your child has not made reasonable progress, it will be important to agree with the school what should happen next. The school may consult specialist advice from any number of professionals, listed below and on page 68.

Any recommendations made by an external professional should be included in your child's next learning plan, outlining how the school has implemented the advice. A completely new learning plan is only needed if significant changes to support or targets are required.

You and the school can also check your local authority's Local Offer (details on page 96) for support that could help your child to achieve their targets.

Special Educational Needs and Disabilities (SEND) teams

Every local authority in the UK is required to have a SEND team. They have a duty to identify, assess and support children and young people with SEND. Your child does not need to have a formal diagnosis of a condition or SEND to access support as provision is based on your child's needs.

Across all nine counties in the South East, SEND teams perform similar core functions while being structured or named slightly differently. Access to services can also vary between counties and every area has a different referral process which you will need to follow.

Check your local authority's Local Offer (details on page 96) for details of which services your area provides, their details and the referral process. Within each team, there are various services which may include:

Educational Psychology Service

This service is for children and young people from birth to the age of 25. All educational psychologists employed are registered with the Health Care Professions Council and have specialist training and qualifications in child development, psychology and education.

Educational psychologists work with children, families and schools to assess learning needs, provide psychological support and advise on strategies to improve educational outcomes.

Autism Advisory Service

This service supports education settings with children and young people who have a diagnosis of autism. It offers tailored strategies, training for staff and direct advice to families and schools. Read more on diagnosis on page 8.

Sensory Needs Service

This service provides advice, support and training for schools and education settings about the needs of children and young people who have a clinical diagnosis of deafness, vision impairment or a physical disability.

The team often works with children and young people from birth to the age of 25 at home, in Early Years' settings, schools and in further educational colleges. It also supports families from the point of diagnosis and provides support, particularly at key times such as transition to a new school or college.

The Early Years SEND Specialist Service and Portage Service

Find more information on page 15 and 16.

SEND Assessment and Planning Team

This team co-ordinates Education, Health and Care Needs Assessments (EHCNA 🔍), Education, Health and Care Plans (EHCP 🔍) and ensures children and young people with SEND get the support specified in their plans.

Understanding the Education, Health and Care Needs Assessment (EHCNA) and Education, Health and Care Plan (EHCP)

Before seeking an EHCP, you should try to work with your child's school to implement the graduated approach. The **graduated approach** exists to ensure children with SEND access early support when they need to and to prevent escalation. If you and/or the school feels you have exhausted your child's school's SEND support, the next step is to request an EHCNA from your local authority to determine whether an EHCP is needed.

- **EHCNA** – an EHCNA, or Education, Health and Care Needs Assessment, is a statutory process that assesses a child's or young person's needs and considers what further provision may be appropriate to support them. The education assessment will cover all four areas of SEND as discussed on page 10 .
- **EHCP** – an EHCP, or Education, Health and Care Plan, is a legally binding document that outlines a child's or young person's SEND needs. It brings together support from education, health and social care services, detailing the personalised support required to help them succeed and prepare for adulthood, beyond what is typically provided in mainstream settings. The local authority and all services named in the plan are legally obligated to provide the support specified in the EHCP.

If there are no setbacks and the local authority agrees to assess your child and issue a plan, the whole process from initial request to final EHCP takes **20 weeks**.

Caseworkers

For the duration of the process, your local authority should provide you with a point of contact on all letters you receive. This will be the primary contact for any questions or concerns related to the assessment and development of the EHCP 🔍. They can guide you through the process, explain the stages, co-ordinate with professionals and organise meetings with your child's school.

When the EHCP is in place, you should be assigned a named caseworker. The caseworker is responsible for ensuring the plan is properly implemented and will support you through any reviews or updates.

Applying for an Education, Heath and Care Plan (EHCP)

WEEK 0

1

An EHCNA is requested

A request for an Education, Health and Care Needs Assessment (EHCNA) is submitted to the local authority (LA).

BY WEEK 6

2

LA decides whether to assess

The LA should let you know within six weeks if they will start an EHCNA or not.

BY WEEK 16

3

A decision is made

The LA should finish the EHCNA and tell you whether they will be issuing an EHCP.

If they decide not to issue an EHCP, you have the right to request mediation or appeal.

BETWEEN WEEKS 16-20

4

A draft plan is issued

The LA will send you a draft of the EHCP. You have 15 days to comment and request your chosen school.

BY WEEK 20

5

Completion

By week 20 the LA should complete and send you the final EHCP. The LA should review the plan every 12 months.

my family our needs

The EHCNA and EHCP process

Stage 1: Submitting an EHCNA 🔍 request

Across all nine South East counties, an EHCNA can be requested by parents, carers, teachers or any other professional involved with your child. It can also be requested by a young person over the age of 16. While the overall process is similar nationally, the exact route and forms used can vary slightly by county.

Generally, parents, carers or educational settings submit a written request to their local authority's SEND team. This is usually done using a standard form; check your local authority's Local Offer (details on page 96) and search 'EHCP' ↖.

Supporting evidence is required. You should gather as much information as possible for a caseworker to collect. If you need further assistance gathering evidence or understanding the process, contact your local SENDIASS 🔍 (details on page 97). Examples of evidence include:

- **Professional reports** – this could include reports from professionals like educational psychologists, speech and language therapists, occupational therapists or paediatricians, including privately obtained reports.
- **Diagnosis and medical reports** – any diagnosis letters or reports from specialists and medical reports that explain your child's conditions and its impact on their learning. Your child does not need to have a diagnosis in order to get an EHCP 🔍. However, if you do have details of a diagnosis available, you should include them as part of your application.
- **School reports and work** – request copies of your child's school records and any reports from your child's SENDCO 🔍. You can also submit copies of your child's schoolwork with annotations from their teacher if it is relevant.
- **Evidence of interventions** – gather any provision maps or plans from the school that outline support being provided to your child and include your child's progress, or lack thereof, in response to the support provided. This needs to include evidence that the school has completed at least two Assess, Plan, Do, Review cycles and evidence that the school has consulted with specialists and the recommendations have been implemented and reviewed. You will need to show that the school has fully utilised its available SEND resources.

If your child's school refuses to implement SEND provision

It is better to work with the school if you can. However, if this is not possible, the school being unwilling to meet your child's needs is not good enough evidence for an EHCP. You must make clear that even if they were willing, their

SEND provision would not be enough for your child's needs. Show how you've attempted to access their SEND resources. You can include the school's SEND resources (available on the school website) and explain why this is not enough.

The SEND Code of Practice is a valuable resource for determining what support should be provided for your child and, if applicable, where it is not being met. You can speak to a SENDCO or seek to resolve the disagreement (read more on page 32) if you feel your child's needs would be met with the school's provision.

The EHCP process starts from the moment you submit your application. The local authority has **six weeks** to decide whether to proceed with a full EHCNA.

Stage 2: An EHCNA happens

If your local authority proceeds with an EHCNA, a caseworker must seek written advice from a range of people:

- You, as your child's parent or as a young person.
- Educational advice (usually from the head teacher or principal).
- Medical advice and information from a healthcare professional.
- Psychological advice and information from an educational psychologist.
- Advice and information in relation to social care.
- Advice and information from any other person the local authority thinks appropriate.
- Where your child or young person is in Year 9 or beyond, advice and information in relation to provision to assist them in preparation for adulthood and independent living.
- Advice and information from any person you reasonably request that the local authority seek advice from.

If you would like any additional advice from any professional in education, health or social care (such as a speech and language therapist, occupational therapist or physiotherapist), you must request it from a caseworker, as long as it is reasonable. A request would be considered reasonable where, for example, a child has been identified as needing an assessment already and they are on a waiting list, or where the school, college or other professional has said this advice may be needed.

The local authority may not go out of their way to collect any more documentation than you request. It is essential that you know what professionals can be involved so you are able to consider all options. Read more on page 15, 25 and page 68.

The local authority is responsible for collecting all further evidence you request. They will reach out to all professionals you request advice from. Professionals must reply within **six weeks**. They may give advice on your child's needs, the provision needed to meet those needs, and the results expected from that provision from records alone, wherein the evidence will be sent straight to your local authority. In some cases, they may reach out to you to arrange an assessment of your child.

All advice is then considered by your local authority panel to decide whether to issue an EHCP. Your local authority must tell you whether they will be issuing an EHCP by **week 16**.

What is included in an EHCP?

An EHCP is divided into sections A-K

- **A** Views, interests and aspirations of the child/young person and their family
- **B** Special educational needs
- **C** Health needs relating to SEND
- **D** Social care needs relating to SEND
- **E** Outcomes
- **F** Special educational provision

- **G** Healthcare provision relating to SEND
- **H** Social care provision relating to SEND
- **I** Name and type of educational setting
- **J** Personal budget and direct payments
- **K** Advice and information (appendices)

Stage 3: A draft EHCP is issued

Your local authority's SEND team writes your child's EHCP. A draft plan is sent back to you for review and any feedback or changes you may have. Be sure you understand your rights and how to respond. You or your young person will have a specified period for review of at least 15 days. You can submit comments (known as representations) about the draft and request a meeting with your local authority.

Ensure the plan accurately reflects your child's needs, strengths and the support they require and make a note of anything that is missing. Once you agree on the draft plan, a caseworker will apply to the current or named school to seek its views on meeting the requirements identified within the draft plan. Your local authority will consider the feedback and make any necessary changes before finalising the EHCP.

This is also the time you can suggest specific educational settings for your child to be named in the final plan. You have a right to request any school, including mainstream, specialist or independent, however your local authority may not agree to your choice of setting. Your local authority should consult with your preferred schools and may also consult with other settings that they feel are most appropriate to meet your child's needs. The schools have **15 days** to respond. Read more about types of schools and what happens if a suitable school can't be found on page 43.

Stage 4: The EHCP is issued

You will receive a final EHCP by **week 20** and the support for your child will be put in place. If you're not happy with the final plan, you have options to resolve any issues or make an appeal.

Resolving disagreements about an EHCP

Despite your efforts, your application may be refused at any stage. Your local authority has a responsibility to provide reasons in a decision letter which should clearly outline why they believe your child's needs can be met through SEND support alone, without the need for an EHCP. This will immediately 'pause' the process at whichever week your application sits in the timeline.

The local authority may then offer a non-statutory plan to document the identified needs and support being provided. This plan is not legally binding but can be useful for communication and planning. The non-statutory plan is not a substitute for an EHCP and you are not required to accept it as an alternative.

You can meet with a caseworker and you have the right to appeal the decision. There is a statutory process which can be followed to resolve the disagreement.

Sometimes it isn't possible to reach a resolution without the help of a third party. There are different types of formal dispute resolution.

Mediation

If you disagree with a decision the local authority has made about an EHCP, you have the right to try mediation before appealing to the SEND Tribunal. When the local authority sends you a decision letter (for example refusing an assessment or issuing the final plan), they must also:

- Tell you about your right to mediation and provide the contact details of a mediation adviser.
- Give you enough information to understand what mediation is and how it works.

If you decide you want to engage with mediation, you must let the mediation adviser know what issues you want mediation to cover. The mediator will then liaise with the local authority to arrange a mediation meeting. The local authority must then arrange a mediation meeting within 30 days of being informed.

If the local authority does not arrange mediation within that 30-day window, the mediation adviser will issue a 'deemed mediation certificate'. This certificate means you can still go ahead and appeal to the SEND Tribunal.

If you decide not to attempt mediation, you should also let the mediation adviser know; they will issue a mediation certificate that allows you to lodge an appeal.

Mediation is a free, impartial service. You can attend with someone to support you (for example, an advocate or SENDIASS 🔍 adviser). The local authority representative should have decision-making authority.

Mediation is confidential – what is discussed in the meeting is not shared outside the session. If an agreement is reached, it will be put in writing and signed by all parties. If no agreement is reached, the mediator will issue the mediation certificate, which you can use if you decide to appeal to the SEND Tribunal. The discussions themselves cannot be used as evidence in the Tribunal.

If mediation does not resolve the dispute, you retain the right to appeal to the SEND Tribunal.

Disagreement resolution

Some issues (such as how a school or local authority is carrying out its duties) cannot be dealt with through mediation. In these situations, you can ask for a disagreement resolution meeting, which aims to resolve the problem informally. You can ask the independent disagreement resolution service directly for a meeting. Your local authority should tell you the service provider in your area. You can also check your local authority's

Local Offer or ask SENDIASS for help (details on page 96 and 97).

If you are successful in resolving the disagreement, the process will resume from the week it was paused and will follow the standard timeline.

First-tier Tribunal (SEND Tribunal)

Once you have a mediation certificate, you can appeal to the Tribunal. The Tribunal is a legal process that considers appeals against specific local authority decisions, such as refusing to assess, refusing to issue a plan, the contents of a plan, or ceasing a plan. For more information, visit **www.gov.uk** and search 'First-tier Tribunal SEND'.

The Tribunal process can be a lengthy one and cases can take a year or more to be resolved. You have the option to seek legal advice. Some offer limited free consultations, although it is worth noting that lawyers can be costly.

In certain circumstances, other legal routes may also be suitable, such as judicial review or complaint via the Local Government Ombudsman. If you need help, contact your local SENDIASS (details on page 97) or seek legal advice.

Your local SENDIASS (details on page 97) can offer information, advice and support in resolving disagreements about an EHCP.

A challenging process

While obtaining an EHCP may be a relatively simple process on paper, it is important for you to know that it can be time-consuming and potentially frustrating for parents.

With the potential for an EHCNA and EHCP to be refused, a thorough assessment of your child's needs is required, as well as a substantial bank of evidence to determine their eligibility.

Additionally, local authorities have limited resources for EHCP provision. Research your local authority's requirements as much as you can before submitting your evidence.

This is in no way intended to dissuade you from seeking an EHCP for your child. Rather, it is to inform you that the process can be difficult. Despite the challenges, it is important for you to persevere and seek support if needed from your caseworker or local SENDIASS (details on page 97).

So what can parents do?

- **Be clear on your child's needs** – special educational needs are not the same as a learning difficulty or disability. Make sure you are absolutely clear about how your child's learning difficulty or disability requires extra provision. For example, a learning disability like dyslexia doesn't directly prove your child has SEND. However, if their dyslexia means they struggle with reading in the classroom and they can't answer questions without adult supervision or similar, then they require special educational provision to be made for them. Focus on their needs, not their diagnosis. Read more on page 8 and 10.
- **Show the practical impact** – it can be difficult to write about your child negatively, but your local authority must understand their level of need. Their decision is made on paper with minimal personal interaction. Emphasise the practical impact of your child's needs – for example, you might include a piece of their work with a teacher's annotations showing they were unable to complete the task independently.
- **Work with your school, not against them** – even if your child's school doesn't support your application or won't make it for you, when you submit a parental request for an EHCNA, the local authority will ask the school for their advice. If your school is unco-operative, keep the SENDCO 🔍 or teacher informed of what you're doing. Ask them for copies of your child's learning plans for at least the last two terms so you have your evidence and make sure you're happy with them. If not, ask for a learning plan review meeting. Request copies of your child's attendance, attainment and behaviour data. Ask for a copy of your child's timetable showing the provision in place for them.
- **Do local research** – speak to other parents in your area and look online to find out what your local authority will demand and make sure you've included it on your application. Your local parent forum is a good place to start (details on page 91).

Reviewing an EHCP

Your local authority has a statutory obligation to review your child's EHCP 🔍 in its entirety at least annually (or every six months if your child is under five) and is a chance for parents and young people to request changes with supporting evidence, if needed. The review may differ during key transitions, including a Year 6 Transition Review before secondary school and a Year 11 Transition Review before post-16 education.

If a review is not completed within the required timeframe, you should contact your local SEND team (read more on page 25) or EHCP caseworker at the local authority for an immediate review. If the delay is significant and the local authority is unresponsive, you can escalate the issue by making a formal complaint to the local authority, contacting your Local Government Ombudsman (details on page 95) or seeking legal advice.

You can ask for an informal review at any time, which could be an opportunity to discuss how the school is implementing the plan and any concerns you have about your child's progress. An early EHCP review can be requested on specific grounds when:

- There is a major change in a young person's SEND and the plan doesn't reflect this.
- The provision in the EHCP no longer meets their needs.
- The young person has been excluded or is at risk of exclusion from the school.
- There is a problem and it seems the school may not be meeting the young person's needs.

Ceasing an EHCP

In most cases, an EHCP will last until the young person turns 25. Section 45 of the Children and Families Act sets out the circumstances in which a local authority may cease to maintain an EHCP earlier than this. This is when they are no longer responsible for the young person or they decide it's no longer necessary to maintain the plan, for example, if special educational provision is no longer necessary.

When determining whether a young person no longer requires a plan, the local authority must consider whether the educational or training outcomes specified in the plan have been achieved.

If the young person is over 16, they can make the decision to cease the EHCP themselves.

When a young person is close to finishing their education and training, the local authority should use the final annual review to agree on the support needed to help them engage with services after they leave education.

If your young person is progressing to higher education such as university, their EHCP will cease. Other services will be available to support them instead such as their university's disability support service.

Transition assessments in an EHCP from age 19-25

Starting from Year 9, preparing for adulthood planning should be incorporated into your young person's EHCP. The EHCP review and subsequent reviews should include specific targets to help your young person achieve their goals related to preparing for their adulthood. The four areas of preparing for adulthood planning (employment, education and training; independent living; community inclusion; and good health) are discussed on page 47.

Your local authority can decide if an EHCP is no longer necessary for a 19- to 25-year-old. However, your young person may need longer in education or training to achieve their outcomes and make an effective transition into adulthood. Further specialised transition reviews should be conducted to ensure a smooth transition into their post-16 education, training, work and beyond. You can request these reviews in the same way you would for a normal EHCP review.

Students aged 19 to 25 with EHCPs who are continuing in education may have a range of options, including further education, training, a supported internship or apprenticeships (read more on page 48). Local authorities should consider the need to provide young people with an EHCP with a full package of support across education, health and care. They will need to work with providers and young people to ensure there is a range of opportunities that can be tailored to the individual's needs. It may include activities such as:

- Volunteering or community participation.
- Work experience.
- Independent travel training.
- Skills for living in semi-supported or independent accommodation.
- Training to develop and maintain friendships.
- Access to local facilities.
- Physiotherapy.

Young people aged 19 to 25 have the right to request an EHCP even if they have never received one, unless an assessment has been carried out within the last six months.

For young adults, there may be separate assessments for health and social care. These focus on areas such as independent living, employment, community participation and health. The aim is to ensure that education, health and social care services work together to provide a co-ordinated plan of support that helps your young person move successfully into adult life. Read more on health and social care assessments on page 79.

You can also seek independent advice from your local SENDIASS (details on page 97).

NAVIGATING THE EHCP COMPLAINTS PROCESS

After moving from Surrey to Devon in August 2021 with an EHCP in place, our daughter's therapies – physiotherapy, speech, and occupational therapy – were not provided for five months.

We had started the EHCP process back in March 2021 in Surrey and by June it was issued and shared with Devon's SEND team ahead of the move. Despite this, we still experienced issues and had to pursue a formal complaints route in January 2022.

Our timeline of escalating the complaint:

September-November 2021

Repeated calls and emails to the SEND team. No progress.

Mid-November 2021

Finally spoke with caseworker after three months of silence.

December 2021

Escalated to the SEND manager and Head of SEND. Set deadlines for action.

January 2022

Sent a formal complaint letter, using legal wording from SOS!SEN, and copied in the Chief Officer for Children's Services. Warned we would pursue judicial review.

Late January 2022

Private therapists were appointed for Coraline. Provision began at last.

Early February 2022

Formal complaints meeting held with SEND team, NHS and complaints officers. All therapies confirmed and compensation offered for every missed session.

Section F of an EHCP is legally binding from day one and local authorities must provide the therapies listed. Once therapies were in place, our confidence as parents returned. Coraline's school received professional guidance, routines were established and she regained access to vital equipment.

The process was draining and left us exhausted, but it taught us that persistence matters. I have learned that standing firm is not 'complaining' – it is securing my child's rights. You are doing something incredible for your child by standing up for what they deserve and need.

To every parent or guardian reading this, **you can do it**.

Liz Arriens-Troy explains her experience of the EHCP complaints process.

9 TIPS FOR WHEN THE EHCP IS FIRST ISSUED

1 If you don't understand anything in the draft EHCP, **ask for it to be explained** in writing. Never feel rushed into signing until you are confident.

2 **Keep detailed notes** of all phone calls and emails. Include dates and what was said. After calls, send a follow-up email to confirm the discussion.

3 **Seek support** from EHCP advisers, charities and SENDIASS. I used Get on Down's and Skylarks in Surrey. They can attend meetings, explain terminology and explain your rights.

4 **Ask advisors what wording to look out for**. Replace vague terms like 'access to' or 'as advised' with specific commitments such as 'will have'.

5 **Ensure therapy provision in Section F is quantified**. Check it details who delivers it, when, how often, and the number of direct and indirect hours. It's legally binding – if it is not being provided, you can take legal action on sections B, F and I.

6 **You can go private if you're on a waiting list**. If the NHS isn't able to write a report, private reports can be included in the EHCP. You can go to tribunal if it is not included.

7 **Look up useful documents** to inform yourself or quote them in the EHCP, such as The SEND Code of Practice and The SEND Regulations 2014.

8 It takes time. It took six months from EHCNA to sign off for us. So **plan ahead and be kind to yourself**.

9 Feel all the emotions around the process. **Ask for help**. Be proud of yourself for what you've done.

Liz Arriens-Troy's top tips for understanding the EHCP.

Special schools

Special schools provide appropriate placements for children and young people with the most significant needs. The local authority is responsible for the decision to place a child or young person in a special school. You can express your preference for a school, including a special school. A special school placement typically requires an EHCP.

A multi-agency panel made up of education, health and social care professionals considers individual children or young people with an EHCP where a special school placement is requested and advises the local authority on suitable placements. You can name a specific school or request a particular type of school, which must be carefully considered by your local authority. You or your local authority may also choose a special residential school for your child, which provides both education and on-site living accommodations. Your child may benefit from a residential school if they have complex SEND that requires intensive 24/7 support that cannot be adequately provided in a mainstream or special school setting. You will need an EHCP for your child for your local authority to determine if a residential placement is appropriate. You can also express your preference for a particular SEND residential school.

If your child or young person is successful in a specialist setting, they may return to a mainstream setting at any time following appropriate review of their EHCP. This may occur when they demonstrate a readiness and when the special school, in consultation with you and the local authority, believes it is in your child's best interest. The decision is based on individual progress, your child's needs, and the potential for successful integration into a mainstream setting. You may want to consider mainstream options at times of transition (e.g., transfer between primary and secondary school).

For guidance for making the decision about whether your child or young person would be appropriately placed in a particular special school, visit your local authority's website and search 'Special schools'.

SEND home-to-school transport

Travel assistance can vary by eligibility including distance and age criteria. It is not automatically granted because a child has an EHCP and many children with SEND travel to school without specialist provision. However, some children with specific needs will require additional support, often for an agreed period. In such cases, the local authority will arrange transport to meet the specific needs of the students. For example, if your child is a wheelchair user and the distance to their school is too great to commute, transport may be provided.

This might include public transport, taxi, minibus, wheelchair-accessible vehicle and a bus/coach. In most cases, your child will be required to go to a meeting point local to your home and be collected. You will need to apply formally, providing details about your child's specific needs and any relevant information.

All counties in the South East have transport options for children with accessibility needs. You will need to contact your local authority's SEND team (details on page 95). In some counties, such as West Sussex, personal travel budgets and parental mileage may be alternative provisions.

Home education

Although most children are educated in a school, some people choose alternative education for their children. This is usually done by opting to educate your children in the family home. This type of education must still be efficient and suitable for your child.

If your child has SEND, you have an equal right to home educate. However, if your child currently attends a special school, their name cannot be removed from the roll of that school without the agreement of the local authority. If a child who is home educated has an EHCP 🔍, the local authority remains responsible for ensuring the child's needs are met and should review it annually.

If you are educating your child at home and feel they have SEND, contact your local SENDIASS 🔍 (details on page 97) for advice. You may ask your local authority to carry out a statutory assessment (or reassessment) for an EHCP. Local authorities may fund support for the SEND of home-educated children where it is appropriate to do so, although they do not have a legal duty to provide SEND provision in this situation.

While the legal framework is the same across the country, some local authorities offer specific procedures, guidance or support for SEND families choosing home education. All counties require you to notify your local authority if you wish to home educate your child and any details of their EHCP, which may require you to provide evidence of suitable provision and meet with your child's case officer. Some areas such as Kent offer a dedicated Home Education Team, although this is not guaranteed for all counties. Check your local authority's Local Offer (details on page 96).

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Living

Learning

Working

Independent schools and colleges

The Government produces lists of approved independent educational institutions, independent schools, post-16 institutions (Section 41 Secretary Approved List), non-maintained special schools, and independent schools. To find these, visit **www.gov.uk** and search 'Independent schools and colleges'.

You have a right to request an independent school that isn't SEND specific. If this is relevant to you, you should speak to your local authority caseworker.

Post-16 education

The law requires that every young adult in England continues in education or training until their 18th birthday. This education can be provided through sixth form, college or with a training provider. The young person can complete an Apprenticeship or Supported Internship. Alternatively, full-time work or volunteering can be combined with part-time education or training that leads to a relevant qualification.

Every young adult between 16 and 17 years old is entitled to an offer of a suitable place of learning by the end of September, to continue in education or training the following year. Young people with an EHCP must have the same access to further education until they are 25 years old. Courses at college will be free, provided they are making progress.

You can find out more information about your child's post-16 education options on page 48.

If you can't find a school

If no school is able to meet your child's needs, the local authority still has a legal duty to make sure the SEND provision set out in your child's EHCP is delivered. If the named setting cannot provide what is required, your local authority must look at alternative options. This could include:

- **Alternative provision** – a different setting arranged by the local authority where your child can receive education while a suitable long-term placement is found.
- **Bespoke or personalised packages** – also called Education Other Than at School (EOTAS). This is when education is arranged in a different way, for example through home tuition, online learning or specialist providers. EOTAS can only be named in an EHCP if it is agreed that no setting would be suitable to meet your child's needs.

Your child is entitled to the provision in their EHCP and the local authority is responsible for ensuring this happens.

ETHAN'S PROGRESS THROUGH SCHOOL-BASED SUPPORT AND HOME TUITION

Ethan, a 7-year-old with autism and emotional regulation difficulties was struggling to access learning in his mainstream setting and later moved to home tuition. His sessions were designed around his EHCP and unique communication needs.

Tutors introduced a play-centred approach, integrating phonics, numeracy, handwriting and emotional self-expression. Lessons were flexibly adapted to Ethan's focus, using music, sensory tools and movement-based learning to help him stay engaged. Emotional outbursts decreased as he began to verbalise needs and cope with transitions more calmly.

Weekly progress reports tracked both academic skills (e.g. sentence building, name writing) and personal growth (e.g. coping with change, self-regulation). Collaboration with school staff ensured that the provision was joined-up and consistent with his broader educational support plan.

Most importantly, Ethan began to feel safe, valued and successful. His school recognised the positive impact too, praising the collaborative approach and flexibility. Ethan's story shows how combining academic and emotional support within a consistent framework, while working with all support systems, can lead to meaningful progress for young learners with SEND.

Story provided by Bright Heart Education
www.brightheart.co.uk @brightearteducation

TIPS FOR TRANSFERRING AN EHCP TO A NEW LOCAL AUTHORITY

Liz Arriens-Troy moved from Surrey to Devon with an EHCP in place; here's what she would like to share with other parents.

As soon as you know you're moving: Call the SEND team in your new LA, explain that an EHCP exists, and ask if they will honour the funding and provision. Take notes of the date, contact and content of the conversation. Start a spreadsheet listing all EHCP-related calls, emails and meetings and download important emails.

About a month before your move: Ask your EHCP Co-ordinator to phone the new SEND team to discuss funding and provision. Send the prospective new school a copy of the EHCP yourself. Ask all therapists to contact their equivalent in the new borough regarding referrals.

Just before your move: Confirm that the new SEND team in the new LA has spoken to the new school about funding and provision and when it will be in place.

A couple of days after your move: Ensure a transfer letter is sent from your previous LA with the EHCP, supporting documents and new school details. Record the date in your spreadsheet.

A week after your move: Check the plan has been transferred, therapy referrals made and find out the email for the new Co-ordinator and get in touch.

Six weeks after your move: Within six weeks, the new LA must inform you when they will review the EHCP and whether they will make an EHCNA.

Preparing for adulthood

Your child growing into a young adult can be an uncertain time for parents and carers. Your child will be moving from familiar children's services to new adult services, where they may start taking on decision-making responsibilities for themselves.

Preparing for adulthood involves work being carried out by professionals from education, health and social care, alongside families, to support children and young people to achieve their goals and aspirations.

At different times in your child's life, there will be transitions between stages and services, such as education, health and social care services, and when they move into uniquely adult services like supported housing and employment. Read more on education transitions on page 37 and health and social care transitions on page 81. For young people with SEND, planning for adulthood happens throughout their childhood. If your child has an EHCP 🔍, preparing for adulthood will form part of this plan during Year 9 (the year in which they have their 14th birthday).

If your child does not have an EHCP but has SEND, their school is responsible for the smooth changeover of services during the transition from childhood to adulthood. It is essential to discuss transition planning with your child's key workers (e.g. their teacher, SENDCO 🔍 or doctor) and education and healthcare providers directly about the transition. You can also contact your social worker if your child has one to discuss the transition from Children to Adult Social Care. Read more on page 81.

Five-day offer

This is a supportive framework which focuses on young people aged between 16 and 25 years old with a learning disability who are leaving full-time education. It states that all young people with an EHCP 🔍 should receive a full-time education package equivalent to five days per week. It helps them to develop links around learning, independent living skills, volunteering, paid work and leisure in their local community.

The five days do not have to be at one provider and can include time in different settings and with different providers.

It can include a range of activities to complement the education outlined in an EHCP. The offer is interpreted and implemented slightly differently across local authorities. The five-day offer is explicitly mentioned in some areas, although it may be embedded within other post-16 provision in other counties. Visit your local authority's website and search 'Preparing for adulthood' ↖.

Employment and training

Employment is an important part of life. There are several ways that young people with SEND can access the world of work.

Identifying your young person's strengths, exploring their career options and accessing support services are vital when starting their employment journey. To find lots of useful information, including a skills assessment and exploration of careers and courses on the National Careers Service website, visit **nationalcareers.service.gov.uk**

Your young person's school should provide careers advice and information on different opportunities in school years 8-13. This may be written into their EHCP and if their EHCP extends beyond age 19, all further education and employment goals should be detailed in the plan. Read more on EHCPs after age 19 on page 37.

There may be services in your local area available to help young people with their employment journey. Your local authority's Local Offer (details on page 96) will include details of training, work experience and employment for your young person with SEND. To find out about possible specialist services in your area, such as the Youth Employment Service in East Sussex, visit **www.cxk.org/** You can check this by searching 'Employment for my SEND child in my area'.

Supported Internships

Supported Internships are specifically designed for young people aged 16-24 with SEND who have an EHCP. They offer personalised support from a job coach, helping your young person to develop skills and confidence in the workplace.

Your local authority's Local Offer (details on page 96) is a good starting place to find information. You can contact a chosen provider directly to enquire about their programmes and application process. The application process may involve sharing your young person's EHCP and potentially attending an interview or assessment.

Apprenticeships

If your young person may be able to work more independently, an apprenticeship may be the right option. Apprenticeships are paid programmes that combine on-the-job training with off-the-job learning, leading to a specific occupational qualification.

To find an apprenticeship on the Government website, visit **www.gov.uk/apply-apprenticeship/** You can also check the websites of potential employers directly. Colleges and training providers also often offer apprenticeships or can provide information about them. To find support for SEND-specific apprenticeship pathways, visit **nationalcareers.service.gov.uk** and

www.sense.org.uk/information-and-advice/life-stages/childhood-and-school/send/post-16

Traineeships

Similar to apprenticeships, traineeships are shorter, unpaid programmes and focus on developing general employability skills and preparing young people for further training or employment. You can apply in a similar way to apprenticeships.

To find out more information, visit **www.getmyfirstjob.co.uk/WhatsNext/Traineeships.aspx**

Volunteering

Young people with SEND can volunteer in various ways including supporting events, assisting with fundraising or helping in charity shops. Check local charities in your area to see if they have specific volunteer roles.

Self-employment

Venturing into self-employment can be a positive and empowering step in a young person's career path but the right support and advice should make young people feel supported in the leap. If your young person is considering self-employment, consider if they have a clear passion, if they are using their strongest skillset, if they can make enough money doing it and if they have a business vision.

→

→ Self-employment can provide flexibility to work from anywhere, increased independence and freedom, increased job satisfaction and can be a better fit for individuals unable to stick to a rigid routine.

There are schemes available to provide young people with the information and support they need to set up their own business.

To find out about how you can support your young person's self-employment journey, visit the *My Family, OurNeeds* website and search 'self-employment'.

Independent living

Independent living is about young people having choice, control and freedom over their lives. This includes where they live, managing money and support they might need, and developing independence skills.

A young person may continue living with family until it's the right time to move.

They can still become more independent while living with family.

It is important to consider how a property can support a young person's needs. It isn't always possible to find a home that suits exactly, but there may be small things that can be changed to make it work.

my family our needs

EMILY'S BIG MOVE

Emily, 19, who's profoundly deaf and wears hearing aids, now mainly uses British Sign Language (BSL). Moving to a new city to start a new job, Emily prioritised an accessible home;

> **'We have a smoke alarm that wakes us up through vibration if there's a fire, vibrating alarm clocks and a flashing doorbell. [...] we got in touch with Deaf Services and they installed them.'**

Scan the QR code to read the rest of Emily's story.

www.myfamilyourneeds.co.uk

Supported housing

If big changes are needed for a property, your young person may require supported housing. Supported housing is a home that has been designed or purposefully adapted to meet the needs of the young person who requires support or care. This can be your own family home, your young person's own home or specialised housing for people with disabilities. It is usually provided by a housing association, local authority or not-for-profit organisation. Funding usually comes from your local authority's social care budget if they are eligible for a social care support package and sometimes the NHS for eligible health needs. A Disabled Facilities Grant may also be available (read more on page 88).

To read more about supported housing in our housing section on the *My Family, Our Needs* website, visit **www.myfamilyourneeds.co.uk/supporting-your-child/housing-options**

Supported living

Supported living describes a range of services that enable people with additional needs to live as independently as possible in their local community. Usually, it emphasises individual tenancies with tailored support to promote independence. Individuals may have their own flat or room in a shared house, with visiting support workers providing assistance with daily tasks, accessing services and social activities. Residents in supported living have greater control over their living space and support arrangements compared to supported housing. It is typically for people with a mental health need, autism, brain injury or a physical or learning disability.

You can start by contacting your local authority's social services department to request a needs assessment. This will determine the level of support needed and if supported living is appropriate. If eligible, a care plan will be developed, including the level of support required, how it will be delivered and who will provide it. You will have the opportunity to choose a provider.

It is usually funded through a combination of services, including your local authority, NHS Continuing Healthcare (read more on page 76), personal budget (read more on page 81), and sometimes charities or private funds.

Live-in care

If your young person requires 24/7 assistance, they may benefit from a live-in carer. A dedicated carer lives in their home, providing round-the-clock care, fostering a strong relationship with the individual. With this support, your young person can maintain their usual routines and participate in activities they enjoy with the support of a live-in carer. This may be beneficial if your young person has significant care or health needs, or if they require constant supervision. →

→ In the same way as supported living, you will need to contact your local authority's social services department to request a needs assessment. A separate assessment is also available for you if you are your young person's carer to evaluate the support you need to continue caring for them.

If eligible, the local authority may fund all or some of the care through direct payments. This will allow you to manage funds and directly employ a carer, who may be a self-employed carer. If you prefer the local authority to arrange the care, they will provide a care and support plan outlining the needs, support methods and personal budget. Read more on personal budgets on page 81.

Consider looking for agencies that specialise in young people's live-in care or self-employed carers. It is important to consider the qualifications, experience and personality of the live-in carer before proceeding to ensure they are the best fit for your young person.

Residential care and nursing homes

Residential care provides a supportive and safe environment 24/7 when independent living is not feasible. This type of care offers accommodation, personal care and emotional support. You and your young person may also consider nursing care for those with complex and specific health needs. They both offer a home-like environment, often with individual rooms or apartments and communal living spaces. They may include adapted bathrooms, sensory rooms, accessible kitchens and other equipment to meet your young person's needs.

You can start by contacting your local authority's social services department to request a needs assessment. This will determine the level of support needed and if residential or nursing care is appropriate. If eligible, you can explore different options, including those provided by the local authority or private providers. If the local authority is involved in funding the care, they will conduct a financial assessment to determine how much you'll need to contribute. You can also arrange and fund residential care privately without involving the local authority. Read more on finances on page 81 and 85.

Getting out and about

Everyone wants to have fun, enjoy life and follow interests. Your local SENDIASS 🔍 (details on page 97) will include information on how to get out and about. Many include activities and day opportunities in your area, information on travel, public transport, learning to drive and how to apply for the Blue Badge parking scheme.

Friends, relationships and community

It is important to support, develop and maintain friendships and relationships so that young people can access their community and feel safe and confident. Your local SENDIASS 🔍 (details on page 97) will include activities, community groups, clubs and support groups.

Understanding sexual relationships and health is essential for young people. Equipping your young person with knowledge, confidence and the ability to navigate friendships, boundaries, online interactions and consent in a safe and respectful way is vital.

To find information and tools for talking to your young person about sexual relationships and health through the NSPCC website, visit **learning.nspcc.org.uk** and search 'talk relationships' ↖.

my family our needs

DANII'S DATING DIARY

Danii's progressive deafness was picked up when she was five. At the age of 12 she was given hearing aids to wear and at 16, her hearing went completely in one ear and never came back.

> **'When I went on a first date, the guy asked my friend the best quiet restaurant to take me to, asked me all about my deafness and even visited me before the date so we could chat in a quiet environment.'**

Speaking of another occasion, Danii recounts her date had 'actually emailed the cinema beforehand and took me to a subtitled viewing. There are good guys out there!'

> **'I'd say to other deaf young people worried about dating - embrace your deafness. Don't dare try and push it down.'**

Scan the QR code to read the rest of Danii's story.

www.myfamilyourneeds.co.uk

Assistive technology checklist

It's a good idea to consider the following questions before buying any assistive technology. If you are unsure about what technology might help meet your young person's needs, you can contact your local authority.

You can download and print this checklist at **www.carechoices.co.uk/checklists**

Suitability

Does the equipment support their specific needs? ☐

Are they willing to use it? ☐

Will it fit into their everyday life and routine? ☐

Have they tried a demo of the equipment? ☐

Do they understand what the equipment is for? ☐

Do they need to take it with them when they leave the house? Is it transportable? ☐

Does the equipment have any limitations that would make it unsuitable for them? ☐

Will it work alongside any assistive technology they already have? ☐

Usability

Is a simpler piece of equipment available? ☐

Does the equipment need a plug socket and will any wires cause a trip hazard? ☐

Is it easy to use? Can they read/hear it clearly? ☐

Are they able to use it? Are there any aspects they don't understand? ☐

Will it need to be installed by a professional? ☐

Can the retailer provide them with training in using the equipment? ☐

Reliability

Will it work if they have pets or live with other people? ☐

Have you and your young person read reviews of the equipment? Consider these before making your purchase. ☐

Can you and your young person speak to someone who already uses it? ☐

Does it require batteries? Find out how often they will need changing and whether the equipment will remind them to do this. ☐

Is it durable? If they drop it, is it likely to break? ☐

Cost

Do you know how much it costs? ☐

Will there be a monthly charge? ☐

Are there alternative solutions that might be free? ☐

Is there a cost associated with servicing the equipment? ☐

my family our needs

Want a guide in your area?

Please let us know if you think a guide in your local area would be useful.

You can do this through our feedback form by scanning the QR code or visiting **www.myfamilyourneeds.co.uk/publication-feedback**

🌐 **www.myfamilyourneeds.co.uk**

✉ **hello@myfamilyourneeds.co.uk**

X @weareMFON
f @weareMFON
@wearemfon
in @My-Family-Our-Needs

Good health

It is important for young people to be aware of their health needs and how to look after themselves as they grow up and become more independent. There is a range of health services available for everybody, including young people with SEND. These include GPs, hospitals, dentists, pharmacists and opticians. In some cases, young people may need to access specialist services, which may be different depending on need.

The doctor's practice learning disability register

Anyone of any age and any level of disability can be on the register. An individual can join the register even if they live alone or do not receive much support in everyday life. Being on the register can help put any support in place before moving into adult services.

You or your young person can contact your local doctor's surgery to be on the learning disability register. An appointment will take place where a doctor will ask about details of your young person's learning disability and the kind of support they need. You can mention reasonable adjustments and support they need to make it easier to book an appointment and visit the doctor's surgery.

You do not need to prove that your young person has a learning disability and you do not need to receive any disability payment or support from social services to be on the register. It can be helpful to mention things like receiving extra support at school, any benefits or support they receive, things they need day-to-day help with, or things they find hard about visiting the doctor's surgery.

The learning disabilities Annual Health Check

While anyone of any age can be on the learning disability register, only those aged 14 and over are eligible for a learning disability Annual Health Check. The Annual Health Check is a free, yearly appointment with a GP or Practice Nurse for young people on the doctor's practice learning disability register. It is completely voluntary.

In the annual appointment, the doctor or nurse will ask questions about keeping well and find out whether any extra help is needed. With consent, they will also check physical health such as weight, heart rate and blood pressure. They may ask for a urine sample or blood test and will also look at any medication to make sure that this is still correct. It is a good time to ask the GP or nurse any questions or worries that you or your child have about their health.

You or your child can ask the doctor to give a health action plan which details things needed to keep your child healthy. It may include things like getting enough sleep or talking to someone when they feel worried. It may also detail how they will access the support they need with their health.

My Family, Our Needs Transition checklist

This checklist helps families explore what their young person hopes to achieve during their transition. It is designed to keep track of the young person's wishes and identify where they may need extra support in the future.

You can download and print a longer version of this checklist at
www.myfamilyourneeds.co.uk/support-child/transition-checklist

Future Planning and Independence

Have you discussed your young person's hopes and goals for adulthood? ☐
Do they understand their options for further education, training, or work? ☐
Are they supported to make decisions about life after 18, including housing, finances and independent living? ☐
Have they had opportunities to take on responsibilities and develop new skills? ☐

Health, Wellbeing, and Support

Is there a clear plan for managing ongoing or changing health needs? ☐
Do you know where your young person can get help for mental health or wellbeing concerns? ☐
Are support networks, including local groups and charities, adapted to meet your young person's needs? ☐
Is your young person building positive relationships with their support team? ☐

Communication and Guidance

Have you received clear information about social care assessments and reviews? ☐
Can your young person ask questions and review their transition plan regularly? ☐
Have children's and adult services worked together to support your young person? ☐
Can your young person access advice and information suitable for their age and understanding? ☐
Does your young person feel supported to discuss relationships, personal choices and career plans? ☐

UNIVERSITY SUCCESS AND HER DREAM CAREER: CHARLOTTE'S STORY

Three years ago, my epilepsy diagnosis at 18 put my dreams of going to university on the line. Despite a heart-breaking results day and further rejection, I have now completed two degrees and found my dream job.

In 2022, I started my second year studying my second degree: speech and language therapy at the University of Manchester. This was both exciting and nerve wracking for me, because it was my dream course. I was offered, and asked for, lots of help, as I did with my first degree. Having now graduated, I feel a lot of pride for believing in myself when times were difficult and gratitude for having such a wonderful support network. I was very close to quitting at one point. It was my final year, I had a lot going on in my personal life that was impacting my mental health, seizures and academic performance.

A turning point for me was the support I received from my personal tutor. She really saw me, she knew how capable I am and fought my corner. Her advocacy boosted my confidence in my own abilities, pushing me to stick with it.

Another turning point was the decision to leave a toxic relationship. I was able to focus on rebuilding my self-esteem, health, studies, and putting myself first. I am now in a long-term, supportive and happy relationship that has significantly contributed to my professional and personal life.

I am ecstatic to say I am now a paediatric speech and language therapist within a SEND school. Knowing that I am contributing to children's future independence and communication development is a feeling that I cannot compare to anything else. I chose to disclose my epilepsy explicitly after I was taken onboard. I have a supportive and inclusive team who took me in as part of the family. So, when I do need to discuss my epilepsy, I am met with understanding and empathy.

I would say to myself and other young people, you are not the sum of a few marks on a piece of paper, you are a multifaceted person. The world is huge, and you have so much time to achieve your dreams.

ACHIEVING YOUR CAREER GOALS: ANNIE'S STORY

From the start of my career, I never let epilepsy define me. Now in my role, I've learned that my skills and personality matter most and epilepsy is just one part of me.

I work as a team administrator in digital and marketing. I started with school admin through an apprenticeship before moving up into retail a couple of years ago.

When searching for my job, I went with myself and my abilities at the forefront of my mind and epilepsy more towards the back as that's not something that should matter to them. Once people see epilepsy, many realise it's not as scary as it's made out to be.

I never see myself as too different from everybody else, but when my seizures started becoming more frequent in the office I would sometimes have to go home. This led to my boss making the decision to get me a laptop instead of a desktop PC so I could work from home. My employer has also always been good at making sure I'm OK and it's reassuring that if I ever feel I need extra support, they will be there for me.

A few of my closer colleagues know about stresses my epilepsy can cause and various horror stories I have but most of the time the questions they ask are based around how I knew I had it and how I cope with it which I find comforting in a way because you know that these people care about you. For me, questions have never got too personal, mainly just people hoping I am OK. This led to a few of them asking what kind of epilepsy I had and the kind of seizures I have which I didn't mind at all.

To a young person with epilepsy who is beginning their journey into employment, I'd say not to let your epilepsy outshine your skills and personality. Of course, your epilepsy will come up, whether that be in your interview, induction or on the job but that definitely isn't your defining feature! If you show who you are outside of that, you should be fine!

Stories provided by Young Epilepsy **www.youngepilepsy.org.uk @youngepilepsy**

Change of legal status and decision making

The Mental Capacity Act (MCA) is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over.

It covers decisions about day-to-day things like what to wear or what to buy for the weekly shop, or serious life-changing decisions like whether to move into a care home or have major surgery. Examples of people who may lack capacity include those with:

- A severe learning disability.
- A brain injury.
- A mental health illness.
- A stroke.
- Dementia.
- Unconsciousness caused by an anaesthetic or sudden accident.

Someone can lack capacity to make some decisions (for example, to decide on complex financial issues) but still have the capacity to make other decisions (for example, to decide what items to buy at the local shop).

Appointeeship

If someone who is over 16 lacks the capacity to manage their finances, you can apply for the right to deal with their benefits for them. This is called appointeeship. Only one appointee can act on behalf of someone who is entitled to benefits (the claimant) from the Department for Work and Pensions (DWP 🔍).

Appointees can be:

- Individual appointees, such as a friend or relative.
- Corporate appointees, such as a solicitor or local authority.

To find out more, visit **www.gov.uk** and search 'Becoming an appointee'.

Lasting Power of Attorney (LPA)

An LPA is a legal document that lets young people appoint someone to make decisions on their behalf if they become unable to make their own decisions. It can be about finances or about health and social care. The young person must be 18 or over and have the ability to make their own decisions when they make the LPA.

If they do not have mental capacity, they may need a court-appointed Deputy.

Deputyship

A Deputy is someone appointed by the Court of Protection to make decisions for someone who is unable to do so alone. A Deputy is responsible for doing so until the person they are acting for dies or is able to make decisions on their own again. To find out more, visit **www.gov.uk/power-of-attorney**

Mental Health Act (MHA)

The MHA is a law that can be used to provide support and treatment to people with a diagnosed mental illness. Being detained (also known as sectioned) under the MHA is a legal process that starts when an approved Mental Health Practitioner has assessed that someone is not safe to be at home and needs to be kept safe while they are being assessed/treated. This law protects people's rights. To find out more, visit **www.nhs.uk** and search 'Mental Health Act'.

Advocacy

Advocacy means having someone to help a person be heard, understand their rights, and be involved in decisions about their life. It can include support to express their views and wishes, secure their rights, and make sure their needs and interests are represented. To find out more, visit **www.voiceability.org**

WHAT ARE THREE TRUTHS ABOUT LIVING WITH A PERSON WITH SEND THAT YOU WISH EVERYONE KNEW?

1. It's a journey that teaches patience. Milestones, big or small, are celebrated with pure joy.

2. Coraline is a child first and foremost, with likes, dislikes, happiness, and sadness – just like any other child. She knows how to get what she wants and if she doesn't want to do something, she won't.

3. As parents of a child with additional needs, it's up to us to create an attitude and expectation that things will generally go well. Challenges and setbacks will come, but dwelling on them doesn't help. Then you are able to keep moving forward, even if these setbacks sometimes slow you. You will soon be on the up once again.

Kevin, Coraline's father

1. As her parents, we are just parents like any other.

2. Appointments – medical or therapy – are frequent. You learn to adapt. We absorbed new terms like 'sensory defensiveness' and 'sensory seeking,' which explained why Coraline struggles when people enter her space. I knew my role was to keep her occupied and calm while the professionals did their work.

3. Our child brings us joy, just like any other child. Despite challenges, the experience, love and happiness she gives are enormous. Some days can be intense and exhausting at times, but our day-to-day is also full of discovery, love and pride.

Liz, Coraline's mother

Health services

Health services in your area include GPs, pharmacists, dentists, opticians and hospital services. These universal services are available to everyone. To find the nearest service to you, visit the NHS website at **www.nhs.uk** and input your postcode for local information. Children with SEND may need more support. This could be from different health services at different stages in their lives.

It may be beneficial for your child to be on the doctor's learning disability register which ensures your child's doctor is aware of any additional healthcare needs they may have. Being on the register means they can access Annual Health Checks from age 14 onwards. Read more on page 56.

When transitioning from children's health services to adult services, if your child has an EHCP 🔍, any healthcare provisions and services should be detailed in their plan and included in transition meetings to ensure a smooth changeover.

Health services for everyone

If you have concerns or questions about your child's health, the first person you should contact is your GP, health visitor or school nurse for medical services or your dentist for dental services. GPs can refer you or your child to more specialist services when needed or give advice regarding general health conditions. NHS dental services are free to anyone under the age of 18. To find an NHS dentist near you, visit **www.nhs.uk/nhs-services/dentists/how-to-find-an-nhs-dentist**

NHS 111 can help if you or your child has an urgent medical problem and are not sure what to do. The service can advise on the next steps to take. Call **111** or visit **111.nhs.uk** (for people aged five years old or over).

Healthy Child Programme

The Healthy Child Programme is a country-wide initiative and is delivered through local services including the Health Visiting Team (for children from birth to five years old) and the School Nursing Service Team (for children aged five to 19 years old). It offers a range of public health support for all families with children from pregnancy to age five and beyond. This may include screening, immunisations, developmental reviews and advice on parenting and healthy choices. Contact your local health services to find out about how you can access this programme.

Health Visiting Team

Health visitors work closely with GPs, nurses, midwives and the wider community to provide support and advice to parents and families and can offer resources or signpost to other services available to them. When a child is born, the hospital will notify the Health Visiting Team and the service will write to parents to arrange an initial visit. The Health Visiting Team can offer support with:

- Feeding, sleeping and toileting.
- Keeping you and your children safe.
- Immunisation advice, minor illnesses, child development worries or any other worries you may have about your child's wellbeing.
- Support for you if you are feeling low in mood, anxious or need help with bonding and building a relationship with your baby.

The service also offers routine development reviews around age one and between age two and two and a half; this is part of the Integrated Review process (read more on page 7).

School Nursing Service Team

The service consists of specialist nurses and each team covers a group of schools in a geographical area. School nurses promote healthy living and provide advice to parents or young people about any health concerns they may have.

Secondary health services

Children with SEND may need support from different health services at different stages in their lives. Some children and young people with SEND will have more complex needs and may need more specialist services, also called 'secondary services'.

If the health need is deemed significant enough to impact your child's education, and the relevant therapy will assist them in learning new skills or improving their abilities in a way that benefits their educational progress, this may be included in Section F of their EHCP.

When accessing most secondary health services, the health professional will conduct an initial assessment of your child to understand their needs and your concerns. An action plan may then be developed, outlining the care to be implemented and the goals. The care will then be conducted in a setting you agree

Healthcare professionals who may be involved in your child's life:

on and the service will discuss discharge plans with you once the therapy goals are met.

To find the relevant service, visit your local authority's Local Offer (details on page 96) and search for the specific service you need. For example, for West Sussex, visit **www.westsussex.gov.uk/local-offer** and search 'Physiotherapy'.

Speech and Language Therapy (SALT)

SALT provides speech and language therapy to infants, children and young people from birth to 19 years old who have speech, language and communication needs and feeding difficulties. Your child may also benefit from SALT if they are facing challenges understanding language, expressing themselves or making speech sounds. Early intervention can be crucial, especially for infants with conditions like cerebral palsy or Down syndrome.

To access SALT for your child, you can either obtain a referral from a healthcare professional or self-refer directly to your local NHS service.

Physiotherapy

A Children's Physiotherapy Service works with infants, children and young people from birth to 19 years old who have general developmental delay, movement disorders and complex physical disabilities. They assess and treat a wide range of conditions, including musculoskeletal problems, neurological conditions and developmental delays. The service aims to focus on function and participation in everyday life, helping patients to reach their full potential and improve their quality of life.

To access physiotherapy for your child, you'll generally need a referral from a healthcare professional. You may also be able to access the service through a referral from a school or other professional involved in your child's care. In many cases, self-referral is not possible. Some areas may have integrated physiotherapy services within larger healthcare organisations, while others may have specific teams or services tailored to children with particular needs.

Occupational Therapy (OT)

Occupational Therapists work in the community and school with children from birth to 19 years old who have a range of mild to complex disabilities and difficulties. This includes developmental delay, motor disorders and/or complex physical disability.

They aim to help people participate in meaningful activities and daily life tasks, including self-care, like teaching your child to use utensils (dressing, eating), productivity (work, school) and leisure. OTs may recommend changes to the environment, such as home modifications, or adapt tasks to make them easier for individuals to complete. Your child may benefit from occupational therapy if they experience difficulties with:

- Fine motor skills (e.g., handwriting, using utensils).
- Gross motor skills (e.g., balance, co-ordination).
- Sensory processing (e.g., sensitivity to sounds, textures).
- Cognitive skills (e.g., attention, memory).
- Self-care skills (e.g., dressing, eating).
- Social and emotional skills.
- Conditions like autism, ADHD or developmental delays.

To access occupational therapy for your child, you can either seek a referral through the NHS, such as by speaking with your child's GP, or through social services. You can also contact your local authority to enquire. You may wish to opt for private therapy; ensure that any therapist you choose is registered with the Health and Care Professions Council, according to the NHS. To verify their registration status on the HCPC website, visit **www.hcpc-uk.org**

Children's Psychology Services

Children's psychology services provide assessment and therapeutic support to children and families, focusing on emotional wellbeing and addressing developmental and behavioural challenges. It may be provided by a group of health professionals who assess a child's abilities and identify how best to support their needs. This service supports children from infancy to late adolescence. You should check with your local provider to find out their specific age range. Many focus on children up to 18 years old, while some may extend their support to age 25.

Your child may benefit from this service for many reasons, including managing emotions, behaviours or coping with difficult life events. Specifically, services may be needed when a child is experiencing persistent low mood, anxiety or if their behaviour is challenging or violent.

Concerns about self-harm, anxiety, eating disorders or the effects of trauma warrant professional help. If their mental health difficulties are impacting their development, school performance or social interaction, a consultation with a psychology service is advisable.

To access Children's psychology services, you can begin by consulting your child's GP, school nurse or a teacher. Some local services allow for self-referral. To find services in your local area, search '[your area] children's mental health services' ↖.

While many areas do have access to these services, availability can vary significantly. You should check with your local NHS practice for public provision. Independent and specialist services may also be available. Many children's psychology services are part of larger Child and Adolescent Mental Health Services (CAMHS 🔍), which also assist young people with mental health needs.

Specialist Nutrition and Dietetic Service

Many areas have access to dietetic services which support young people to improve their health by making the appropriate lifestyle and food choices. The team also provides assessment and treatment for those who need therapeutic diets and/or nutritional support. These professionals work with a wide range of conditions, from diabetes and gastrointestinal issues to malnutrition and eating disorders, and may offer support in various settings, including hospitals, community clinics and homes.

Some services like those focused on paediatrics will have a specific age range such as 0-18 years, while others may focus on people aged 16 and over. In some cases, there may be specialist programmes for children under five.

To access dietetic services for your child, you'll need a referral from a healthcare professional, such as a GP. Self-referrals are generally not accepted. The specific referral process will vary depending on your location and service provider, but you can find this information on the provider's website or by contacting them directly.

While many areas do have access to dietetic services, availability can vary. You should check with your local NHS practice for public provision. Independent and specialist services may also be available.

Children's Community Specialist Nursing Service

Specialist Nurses provide nursing to children and young people from birth up to the age of 18 who:

- Need acute short-term interventions to enable them to be cared for at home.
- Have complex healthcare needs/ long-term conditions requiring nursing support/intervention.
- Require palliative and end of life care. →

→ Some of their care duties may include:

- Delivering direct, clinical nursing care.
- Supporting families by providing education, advice and support with managing your child's health condition.
- Care co-ordination, including working with other healthcare professionals like GPs, hospital staff and therapists.
- End of life palliative care.
- Mental health support.

While many areas do have access to dietetic services, availability can vary. You should check with your local NHS practice for public provision. Independent and specialist services may also be available.

Social Care Occupational Therapy (SCOT)

Different to OTs 🔍, Social Care Occupational Therapists (SCOT) focus on enabling people to live well within their communities, particularly when facing social isolation or challenges within their social environment. This team can give you advice and information on moving and handling issues, seating at home and housing needs, and can provide assistive equipment and adaptations to overcome some of the difficulties.

Your child may benefit from this therapy if your child is experiencing functional difficulties impacting independence, a disability or developmental delay, or facing challenges that impact their home and community life. This could include challenges with moving in and out of bed or wheelchairs, or limited access to their home, bedroom or bathroom due to physical barriers or posture support. SCOTs can also provide support and training to parents on how to manage a child's needs and promote their independence.

To access social care occupational therapy for your child, you can either be referred by a professional or request an assessment from your local authority's social services. The service is offered across the South East and many are employed by the NHS, while a significant number work within social care and housing services provided by local authorities.

Specialist Dental Service

Some children and young people's health needs mean that they struggle to access ordinary dental services. A Specialist Dental Service supports people who have a physical, sensory, intellectual, mental, medical, emotional, or social impairment or disability which makes routine care in general dental practice unsuitable or impractical for their needs. These services offer specialised facilities, expertise and support to ensure children receive appropriate and safe dental care.

Patients are only accepted by the service via GP referral. To find out more, contact NHS England on **0300 311 2233**. You can also call the NHS non-emergency number on **111**.

Specialist dental services vary by region. You can find out more by visiting your local NHS website or contacting your local dentist to find out if this care is available in your area.

Community Paediatrician Service

Community Paediatricians are specialist doctors who assess and support children with neurodevelopmental conditions, complex health needs, disability, developmental delay and other concerns. These services are often, but not necessarily always, the gateway to autism and ADHD 🔍 assessments, learning disability diagnoses and co-ordinated multi-disciplinary care.

The referral process is generally consistent across all counties and must be made by a professional such as a GP, health visitor, SENDCO 🔍 or other Early Years' practitioner. Many counties require an EHA 🔍 prior to assessment. Read more on page 13. To find out if this service is available in your area, visit your local NHS website and search 'Community paediatrics'.

my family our needs

A Q&A WITH DAVE JEREB, PAEDIATRIC OCCUPATIONAL THERAPIST AND AUTHOR

My Family, Our Needs: How can parents effectively communicate with teachers to ensure their child’s unique needs are understood and met?

Dave Jereb: It really depends on having good communication. The ideal is that both parent and teacher and anyone involved in the child’s life are sharing information. Maybe it’s letting them know they had a bad night’s sleep so they can predict what might happen, sharing strategies that work for them or asking for information.

You do need to advocate for your child and advocate for change, but you’re not going to change the teachers’ behaviour by going in guns blazing. Relationships are key and, while I know that’s hard sometimes, that’s going to be the best way.

Scan the QR code to read the full interview.
www.myfamilyourneeds.co.uk

NHS Wheelchair Service

If your child is experiencing a diagnosis that makes walking difficult, such as cerebral palsy, muscular dystrophy or spina bifida, they may benefit from a walking aid. To obtain a specialised stroller, you will need to be referred to your local NHS wheelchair service department by a health professional like an OT🔍, physiotherapist or GP. They will be able to assess your child's needs and your local NHS wheelchair service will provide a wheelchair that meets your child's mobility needs, free of charge.

If you prefer a different wheelchair that the NHS cannot provide, you may be entitled to a Personal Wheelchair Budget (PWB). The PWB will be enough money for the wheelchair the NHS recommends based on your needs but you will need to add money to the budget if the wheelchair you want is more expensive. The service will need to ensure the chair you choose is suitable and meets your child's needs.

The NHS wheelchair service is responsible for handling repairs and maintenance and providing you with contact details for its maintenance service.

If the NHS recommends a wheelchair that does not meet your needs, you can challenge the decision of your wheelchair assessment by filing a formal complaint with your local NHS wheelchair service, seeking reassessment or escalating to your Local Government Ombudsman🔍 (details on page 95) if necessary.

There can be waiting lists for assessments and for the provision of equipment. If your child receives the high-rate mobility component of Disability Living Allowance (DLA🔍) (read more on page 85), you may be able to apply to the Motability Scheme. The Motability Scheme allows disabled individuals to lease a buggy, wheelchair, car, vehicle or other equipment by exchanging their mobility allowance. To find out your eligibility and equipment on offer, visit **www.motability.co.uk**

If the NHS cannot provide the necessary equipment, or you encounter long waiting times, consider exploring charity funding in your area. To find help with accessing specialist pushchairs and equipment for disabled children on the Family Fund website, visit **www.familyfund.org.uk**

To find additional help on the Whizz Kidz website, visit **www.whizz-kidz.org.uk**

Across the South East, there are various wheelchair service providers which operate differently depending on your county. Your local NHS wheelchair service should provide you with information about the providers in your area, signposting to local suppliers or charities. Visit your local NHS website for details of your local wheelchair service.

Continuing Healthcare (CHC)

Children with complex needs may need additional health support beyond that which is routinely available from mainstream or specialist health services alone, such as GP practices, hospitals or in the community. Any child or young person up to age 18 who has a complex health need, such as a long-term illness or disability, may be eligible for continuing care.

If eligible for NHS Continuing Healthcare (NHS CHC), your child will receive a package of care, which includes a full range of services, support and healthcare funded by the NHS. This covers the cost of healthcare, personal care, care home fees and home support, if applicable. It can also include respite care (read more on page 92). The care package is reviewed periodically to ensure it continues to meet your child's needs.

Planning for the transition to adult services should begin when your young person is 14, with a formal reassessment occurring when they are aged 16-17 to determine their eligibility for CHC upon turning 18. Read more on the transition to adult health and social care services on page 81.

To access CHC for your child, you should speak with a health or social care professional currently involved with your child's care, such as their GP, a community nurse or social worker. They can assess your child's needs and determine if a referral for Children's Continuing Care is appropriate. If necessary, the professional will refer your child to the relevant Integrated Care Board (ICB) for a full assessment.

The ICB will use the National Framework for Children and Young People's Continuing Care to assess your child's eligibility. To check this, visit **www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework**

While the Children and Young People's Continuing Care National Framework provides overarching guidance, the assessment processes can vary slightly between counties in the South East. While the ICB oversees assessments, a local team will conduct the evaluation.

Although the core principles remain consistent, it's essential to contact your local ICB or NHS service for specific guidance on the assessment process.

Palliative care

Palliative care is for people living with a terminal illness where a cure is no longer possible. It is also for people who have a complex illness and need their symptoms controlled. Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Support may involve medicines, therapies and any other aid that specialist teams believe will help.

Palliative care also includes caring for people who are nearing the end of life. This is called end of life care. The goal is to help everyone affected by the diagnosis achieve the best quality of life.

There are several charities there to help support families where children are receiving palliative or end of life care, whether through home visits, advice, emotional, practical or financial support. Many of the organisations support families from diagnosis to the end of life and throughout bereavement.

Demelza Hospice Care for Children

Web: **www.demelza.org.uk**

Evelina London Children's Hospital

Web: **www.evelinalondon.nhs.uk/our-services/hospital/palliative-care/overview.aspx**

Naomi House & Jacksplace

Web: **www.naomihouse.org.uk**

Rainbow Trust Children's Charity

Web: **www.rainbowtrust.org.uk**
Tel: **01372 363438**

Rowans Hospice

Web: **www.rowanshospice.co.uk/palliative-care-support-hub**
Tel: **0239 225 0001**

Shooting Star Children's Hospices

Web: **www.shootingstar.org.uk**
Tel: **0208 783 2000**

Together for Short Lives

Web: **www.togetherforshortlives.org.uk/get-support**
Tel: **0808 808 8100**

Children's Social Care

Children's Social Care services are provided by local authorities and are designed to support children and young people to live independently or to receive the appropriate level of support to live well. Access to services is subject to an assessment of need to determine what level of support local authorities could provide and what support may already be available in the community. These assessments are the process by which information about young people and their families and carers is gathered.

Your child may benefit from social care if they have a long-term health condition, SEND or other complex needs that require assistance.

If your child is under 16 and eligible for social care, you may not have a financial assessment and are unlikely to pay anything towards their care.

If your young person is aged 16 or 17, they may have a financial assessment to look at any money they have, but they would rarely have to pay for their care. If the assessment determines they will receive direct payments, they can manage those finances themselves or they can choose someone to manage on their behalf. Read more on direct payments on page 81.

Your child will need to have an assessment before the local authority can recommend services such as:

- Equipment like a walking frame or personal alarm.
- Changes to your home, such as a walk-in shower.
- Practical help from a paid carer.
- Access to day centres and lunch clubs.
- Moving to residential care.

The Children's Social Care Assessment

To request a Children's Social Care assessment, visit your local authority's website (details of which can be found on page 95) and search 'Needs assessment' ↖. This is the first point of contact. You will need to provide as much information as you can, including whether your child has SEND.

In a children's social care assessment, information is gathered from your child and family and could lead to the provision of services or closure of the case if no further action is needed.

A needs assessment can happen face-to-face, over the phone, online or by self-assessment.

→

→ In most cases, a social worker from your local authority will talk to your child, you and your family and other involved professionals such as teachers and doctors. Often, they will visit the family home and observe the living environment and may interview your child if they have the capacity.

Your child's physical, emotional, social and educational development will be assessed, including their ability to perform daily tasks, communicate, learn, and participate in social activities. They may also assess your ability to meet your child's needs, family relationships and support networks.

There will then be a consideration of what support is already in place for your child, including informal support from family and friends and formal support from healthcare, education and other services.

Your local authority analyses all the information to determine what additional support your child may require to meet their needs and promote their wellbeing. They will then make a decision about whether your child is eligible for social care services. The assessment typically aims to be completed within 45 working days from the date of referral. The specific duration can vary depending on the complexity of the case and your local authority's procedures. Your local social care team will let you know when the assessment is starting, keep you informed throughout the process and share the completed assessment with you.

If eligible, your local authority will then work with you and your family to co-produce a care and support plan. The plan will include:

- A needs assessment of your child's needs and your needs as a carer.
- The specific services and support your child will receive.
- Clarification of the responsibilities of the local authority, you or other relevant agencies.

You will have the opportunity to review the draft plan, share your feedback, suggest changes or additions and for these to be recorded within the assessment before it is signed off. The social worker will maintain contact with the family and provide ongoing support and guidance. You can also request a meeting with the social worker to discuss the plan and any concerns you may have. The final plan will be agreed upon by all parties.

If you're not happy with the final plan, you can challenge it through your local authority's complaints procedure. If your concerns are not addressed, you can escalate the issue through involving your Local Government Ombudsman 🔍 (details on page 95) or seek legal advice (read more on page 34).

Personal budgets

If your child is eligible for support, rather than being allocated services from the local authority, you may receive social care support in the form of a personal budget. A personal budget is money from your local authority that helps towards funding your child's care and support. This is also called direct payment funding, paid monthly.

Direct payments give you more flexibility and choice to arrange and purchase support or services in the way that best suits your child. The services you choose will meet agreed outcomes, needs and your child's circumstances. The personal budget does not count as income and will not affect any benefits. There is no maximum amount of money your child can receive from a personal budget.

The personal budget can pay for:

- A personal assistant to help with everyday care.
- Equipment not provided by the NHS.
- Leisure or educational activities and transport costs to meet a social care need.
- Respite care.
- Anything agreed in your child's support plan that will help manage their condition.

You may not be financially assessed if your child is under 16 and you are unlikely to pay anything towards the personal budget. Young people aged 16 or 17 will be allowed to manage the budget themselves or nominate someone to manage it on their behalf. While they may be financially assessed for any money they have, it is unlikely they will have to pay towards their budget.

The transition to Adult Social Care

When your child is over 18, social care support is organised by Adult Social Care. If they have been receiving care and support from Children's Social Care, they may be eligible for support from Adult Social Care. It is not an automatic transition.

The transition from children to adult services is planned and co-ordinated with specific assessments to determine further eligibility, levels of support and changes entering adulthood.

Your local authority should begin planning for your young person's transition to adulthood around age 14, with formal transition assessments occurring before they turn 18. Young people have a legal right to a transition assessment if they are likely to need care and support as an adult which you can request from your local authority.

Early communication with your local authority will help ease communication and avoid gaps in support.

→

my family
our needs

We want to hear your thoughts!

We would like your feedback on how useful you have found this guide.

You can complete our feedback form by scanning the QR code or visiting **www.myfamilyourneeds.co.uk/publication-feedback**

www.myfamilyourneeds.co.uk
hello@myfamilyourneeds.co.uk

@weareMFON
@weareMFON
@wearemfon
@My-Family-Our-Needs

- → Be prepared to discuss your young person's needs, any anticipated changes as they transition into adulthood and any support they may require. Stay in close contact with your local authority to ensure you receive information about the timeframe and next steps.

Your young person should also be directly involved in the transition process, with their wishes and views taken into account when decisions are made. If your young person has an EHCP 🔍, it will need to be reviewed as part of the transition and can continue until age 25 in some cases. Read more on EHCPs on page 26.

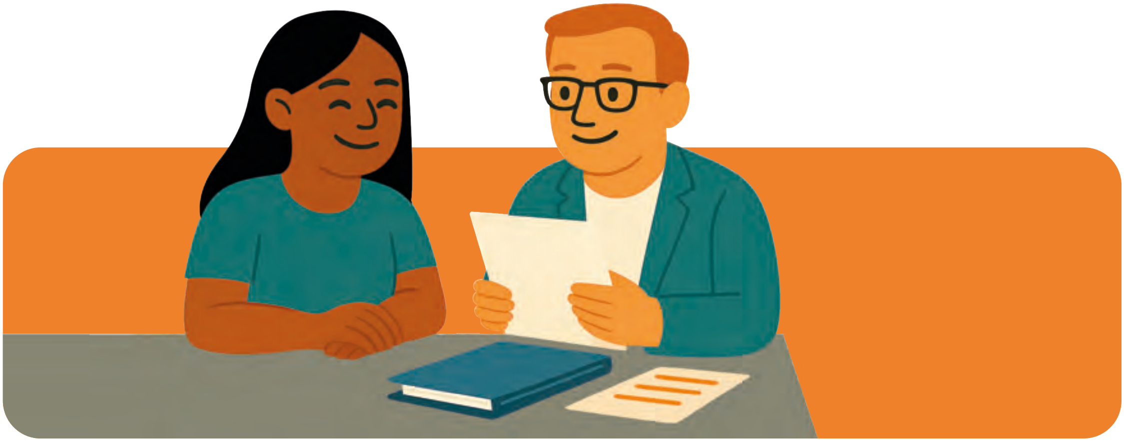
Adult Social Care will need to assess your young person to determine if they meet adult criteria and what level of support they require. If eligible, their existing Children's Social Care support will continue until the adult care and support is in place.

Adult Social Care focuses on supporting individuals to maintain their independence and manage conditions in their daily life, while children's services often involve supporting the whole family. The delivery of care will also be performed by different social workers, healthcare professionals and support staff who weren't previously involved, making the transition process crucial.

As mentioned, your young person's financial situation may also be assessed in order to see if they need to pay anything towards their personal budget, if they receive one, when they transition to Adult Social Care.

If your young person is turning 18 and has not been receiving support from Children's Social Care and you feel they may need support as an adult, contact your local authority for an Adult Social Care needs assessment.

If you do not agree with the outcome of the transition assessment, you can appeal through your local authority's complaints procedure and escalate further if needed – details of how to do this can be found on page 32.



DISCLAIMER: The information listed below is correct at the time of publication and is subject to change. Please check **www.gov.uk/check-benefits-financial-support** for up-to-date information.

There are benefits and tax credits that you may be entitled to. Some benefits can be paid because your child is disabled, while others may be paid to you for other reasons. For example, you may be getting Disability Living Allowance (DLA) for your child and Carer's Allowance as their carer.

Disabled Living Allowance (DLA) for children

DLA for children may help with the extra costs of looking after a child who:

- Is under 16.
- Has difficulties walking or needs much more looking after than a child of the same age who does not have a disability.

The DLA rate is between £29.20 and £187.45 a week and depends on the level of help your child needs.

Your child will need to meet all eligibility requirements set by the Government. Visit **www.gov.uk/disability-living-allowance-children**

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) can help with extra living costs if your young person is aged 16 and over and has both:

- A long-term physical or mental health condition or disability.
- Difficulty doing certain everyday tasks or getting around because of their condition.

Your young person can get PIP even if they're working, have savings or are getting most other benefits.

There are two parts to PIP:

- **A daily living part** – if they need help with everyday tasks.
- **A mobility part** – if they need help with getting around.

Whether your young person gets one or both parts and how much they get depends on how difficult they find everyday tasks and getting around.

It will be paid to your young person unless you are their appointee. Read more on page 61.

To find out more, visit **www.gov.uk/pip**

Universal Credit (UC)

Universal Credit is paid as a single monthly payment. This could include an extra amount to help support your children.

You can get an extra amount for more than two children if:

- The children were born before 6th April 2017.
- You were already claiming for three or more children before 6th April 2017.
- Other exceptions apply.

You might get the extra amount if you start caring for another child, depending on when they were born and how many children you have.

The disabled child addition of Universal Credit helps with the extra costs of bringing up a disabled child.

The disabled child addition will be paid at either a lower or higher rate.

The lower rate is for a child who:

- Receives any rate of either part of Disability Living Allowance (DLA), except the highest rate of the care part.
- Receives any rate of either part of Personal Independence Payment (PIP), except the enhanced rate of the daily living part.

The higher rate is for a child who:

- Receives the highest rate of the care part of DLA.
- Receives the enhanced rate of PIP daily living part.
- Is blind or severely sight impaired.

To find out more, visit **www.gov.uk** and search 'Universal credit'.

Disabled Students' Allowance (DSA)

You can apply for Disabled Students' Allowance (DSA) if you live in England and have a disability that affects your ability to study, such as a:

- Specific learning difficulty, for example dyslexia or ADHD.
- Mental health condition, for example anxiety or depression.
- Physical disability, for example if you have to use crutches, a wheelchair or a specific keyboard.
- Sensory disability, for example if you're visually impaired, deaf or have a hearing impairment.
- Long-term health condition, for example cancer, chronic heart disease or HIV.

You must also be:

- An undergraduate or postgraduate student (including Open University or distance learning).

- Eligible for both a Tuition Fee Loan and a Maintenance Loan (full support) from Student Finance England.
- Studying on a course that lasts at least a year.

The support you get depends on your individual needs and not on income.

To find out more, visit **www.gov.uk** and search 'DSA'.

Free school meals

If you receive certain benefits, your child may be entitled to free school meals, saving you up to £495 per year per child. This scheme is available for school-age children and post-16 students at a school with a sixth form or college.

From the start of the 2026/27 school year, the Department for Education will introduce new eligibility criteria, meaning that all children from households in receipt of Universal Credit will be entitled to receive a free meal.

To find out more, visit **www.gov.uk/apply-free-school-meals**

Holiday Activities and Food (HAF) programme

The Holiday Activities and Food (HAF) programme is a government-funded initiative led by the Department for Education (DfE) to support children and families during school holidays.

Delivered locally by county and unitary authorities across the South East, the HAF programme is for children who are eligible for benefits-related free school meals from age five to 16.

It combines nutritious meals with enriching activities such as sports, arts, outdoor learning and life skills. Many HAFs include places for children with EHCPs or those receiving Early Help support, making it a lifeline for families needing accessible, inclusive support.

Each local authority collaborates with the HAF programme in its area, involving local schools, charities and providers to ensure families can easily access sessions and support of their choice.

For your local area's HAF, search '[your area] Holiday Activities and Food Programme'.

Grants

Across the South East, grants are available to provide support for disabled or chronically ill children and their families. Grants may allow children and their families an improved quality of life, increased independence and more opportunities.

The aid provided by the grants may include specialist equipment, therapy and medical needs, educational support, respite and family breaks, home adaptations, social community projects and more.

For information on what grants are available in the South East, visit **www.disability-grants.org/grants-uk-south-east.html#southeast**

Disabled Facilities Grant

Disabled Facilities Grants are available for children and young people with a disability to make changes to their home. The grant provides up to £30,000, depending on the assessed needs of your child. It usually depends on:

- Household income.
- Household savings over £6,000.

Depending on your income, you may need to pay towards the cost of the work on the property. To check if you are eligible through the AdaptMyHome self-assessment tool, visit **adaptmyhome.org.uk**

You can apply for another grant for the same property if you need to, for example, if your child's condition changes.

It can be used for:

- Access to the dwelling.
- Space to move around to provide care.
- Access to a bedroom, bath, wash basin, toilet, living room and kitchen.
- Safety of the child and family in the home.
- Access to an area of the garden.

You can apply through your local authority. To find out more information, visit **www.gov.uk/disabled-facilities-grants**

If you're not happy with the outcome of your application, you can escalate complaints to the Local Government Ombudsman (details on page 95).

Family Fund

Families can apply for grants from Family Fund for a wide variety of items you feel could help your disabled child and ease some of the everyday pressures you face. These can include kitchen appliances, computers and tablets, furniture, family breaks and day trips, sensory toys, clothing, bedding, and more. Family Fund cannot consider requests where a statutory agency has assessed a need and has a responsibility to provide the item.

You can apply for a grant directly through the Family Fund website. The decision to give a grant is based on your income and the impact of disability on your child. For full criteria and details on how to apply, visit **www.familyfund.org.uk/grants/apply-for-a-grant**

If you have previously received a grant from Family Fund, your family can reapply for further funding after a certain period, depending on your location. In the South East, you can reapply every 24 months. If your circumstances change, you may be able to reapply sooner. Check the Family Fund website for details.

Mobility

If your child has medium- or long-term mobility issues, you may need extra help with the costs of getting to and from appointments. If you are using mobility-related services, you may get help towards additional costs and be eligible for welfare benefits, including grants such as the Family Fund, Motability Scheme or Blue Badge scheme.

Read more on the Motability Scheme on page 75 and visit **www.motability.co.uk** for more information, including about Blue Badges.

Support with debt

Turn2Us is a national charity providing information and support to help you get back on track. Visit **www.turn2us.org.uk** or Citizens' Advice, which also offers advice and practical support.

Finding Local Grants

Many areas in the South East are served by a Community Foundation, which provides grants to local families, charities and projects.

To find funding in your area, search '[your area] Community Foundation grants' ↖.

DISCLAIMER: The information listed here is correct at the time of publication and is subject to change. Please check **www.gov.uk/check-benefits-financial-support** for up-to-date information.

Supporting parent carers and family

Caring for your child with SEND and complex needs means focusing on meeting their needs and those of the family. However, it is important to take care of yourself both physically and emotionally and connect with other parent carers. There is support available for parent carers, both locally in the South East and nationally.

Parent forums are groups run by parents and carers of disabled children from their local area. The aim is to make sure the services in the area meet the needs of disabled children and their families.

Parent carer forums in the South East

Bracknell Forest

Bracknell Parent Carer Forum
Web: **www.bracknellpcf.com**
Email: **bracknell.pcf@gmail.com**
Tel: **07748 310155**

Brighton and Hove

Parent Carers' Council
Web: **www.paccbrighton.org.uk**
Email: **admin@paccbrighton.org.uk**
Tel: **01273 234862**

Buckinghamshire

FACTBucks
Web: **www.factbucks.org.uk**
Email: **admin@factbucks.org.uk**

East Sussex

ESPCF (East Sussex Parent Carer Forum)
Web: **www.espcf.org.uk**
Email: **info@espcf.org.uk**
Tel: **0300 770 1367**

Hampshire

Hampshire Parent Carer Network (HPCN) CIC
Web: **www.hpcn.org.uk**
Email: **participation@hpcn.org.uk**
Tel: **07590 683313**

Isle of Wight

Web: **e-voice.org.uk/parentsvoiceiw**
Email:
catherine@parentsvoice-iw.org.uk
Tel: **07842 152863**

Kent

Parents and Carers Together Kent
Web: **www.kentpact.org.uk**
Email: **info@kentpact.org.uk**
Tel: **07947 563123**

Medway

Medway Parents and Carers Forum
Web: **www.medwaypcf.org.uk**
Email: **info@medwaypcf.org.uk**
Tel: **07813 123984**

Milton Keynes

Parents and Carers Alliance
Web: **www.pacamk.org**
Email: **pacamk@gmail.com**
Tel: **07852 526057**

Oxfordshire

Oxfordshire Parent Carers Forum
Web: **www.oxpcf.org.uk**
Email: **info@oxpcf.org.uk**
Tel: **07394 735666**

Portsmouth

Portsmouth Parent Voice
Web: **www.portsmouthparentvoice.org**
Tel: **07745 205711** (text messages only)

Reading

Reading Families' Forum
Web: **www.readingfamiliesforum.co.uk**
Email: **info@readingfamiliesforum.co.uk**
Tel: **07516 185380**

Southampton

Southampton Parent Carer Forum
Web: **www.sotonpcf.org.uk**
Email: **chair@sotonpcf.org.uk**
Tel: **07907 777053**

Surrey

Family Voice Surrey
Web: **familyvoicesurrey.org**
Email: **contact@familyvoicesurrey.org**
Tel: **01372 705708**

West Berkshire

West Berkshire SEND Parent Carer Forum
Tel: **admin@westberkssendpcf.co.uk**

West Sussex

West Sussex Parents Forum
Web: **wspcf.org.uk**
Email: **office@wspcf.org.uk**
Tel: **07341 183449**

Windsor and Maidenhead

SEND Voices RBWM
Email: **info@svrbwm.org.uk**

Wokingham

SEND Voices Wokingham
Web: **www.sendvoiceswokingham.org.uk**
Email:
info@sendvoiceswokingham.org.uk

Respite care (short breaks)

Respite care provides short breaks for you as a carer. It is a planned period of care that allows you to step away from your caring duties and attend to your own needs while ensuring your child is well cared for. It can involve overnight stays, day care, in-home support or holidays. It is there to help you do leisure activities by yourself, look after other family members, spend time with a partner or do everyday tasks at home and can span anything between a few hours to a week or longer.

Your local authority's social services play a significant role in addressing and potentially funding respite care. You can apply for an assessment through your local authority's social services department online.

There will be a carers' assessment, which evaluates the impact of your caring responsibilities on your life and wellbeing and a needs assessment of your child to understand what kind of care is most suitable.

If eligible, the local authority can provide funded respite care, including short breaks at clubs, activities, care at home or other support services. You can express your preferences for any respite care during the assessment process and discuss desired types of care, frequency and preferred providers. Alternatively, you can ask for a personal budget or direct payments, meaning you may receive money to pay for respite care. You have more flexibility, but it can be more work to organise the care yourself.

You can also privately fund respite care. Charities such as Carers Trust and Turn2Us offer grants and financial support to help with the cost of respite care. Read more on page 85.

Your local authority will send you a report following the assessment and, if you qualify for respite care, your care package will specify the type of respite care and funding you will receive. If you do not receive a care package, you can appeal your carers' needs assessment through your local authority's complaints procedure. You can escalate this to the Local Government Ombudsman 🔍 if necessary (details on page 95).

Holidays for families of children with SEND

Paying for a family holiday is not always easy, especially when there are extra expenses like hiring specific equipment.

Alongside the cost, the logistics of choosing a holiday with the right facilities is vital for an unforgettable experience.

On the *My Family, Our Needs* website, we have a helpful checklist to ensure you've covered all bases before planning your holiday, as well as some holiday recommendations, charities and organisations that can help you find the right break for you and provide financial relief for your holiday.

To find resources, visit the *My Family, Our Needs* website and search 'Short breaks' ↖.

The 3H Foundation

The 3H Foundation supports people with disabilities to have a break, whether on independent group holidays, through family holiday grants or short break activities. The charity also supports adults to have a period of respite, through days out, breaks away or home-based respite hampers. Different aid is available for residents living in certain areas. To find more information on their website, visit **the3hfoundation.org.uk**

Support for siblings

Due to the demands of parenting a child with SEND, supporting their siblings can sometimes be difficult to juggle.

Your SEND child's siblings may be involved in caring for them or may need a little more support with their feelings, attention or understanding of their sibling's disability or needs.

To find a wealth of resources for supporting your sibling child with their emotions, relationships, experiences and hospital stays, as well as top tips and talking about the future on the SIBS website, visit **www.sibs.org.uk**

Are you concerned about a child's safety?

If you're concerned that a child or young person is at risk of harm, neglect or abuse, it's important to take action. Each county has a Children's Services or Multi-Agency Safeguarding Hub (MASH 🔍) where you can report concerns. Anyone – parents, professionals or members of the public – can contact them directly.

You can contact the NSPCC helpline on **0808 800 5000** or your local authority's social services. You can also report online abuse to the Child Exploitation and Online Protection (CEOP 🔍) centre.

Childline provides support and advice for children and young people. Call **0800 111**. Action for Children, Scope and Mencap also provide advice and support:

www.actionforchildren.org.uk
www.scope.org.uk
www.mencap.org.uk

Useful contacts

National contacts

ADHD UK
Web: **adhduk.co.uk**

Barnardos
Web: **www.barnardos.org.uk**

Citizens Advice
Web: **www.citizensadvice.org.uk**

Family Fund
Web: **www.familyfund.org.uk**
Tel: **01904 550055**

Home-Start UK
Web: **www.home-start.org.uk**
Email: **info@home-start.org.uk**
Tel: **0116 464 5490**

IPSEA
Web: **www.ipsea.org.uk**

Kids
Web: **www.kids.org.uk**

Local Government Ombudsman (LGO)
Web: **www.lgo.org.uk**
Tel: **0300 061 0614**

Mencap
Web: **www.mencap.org.uk**
Tel: **0808 808 1111**

National Autistic Society
Web: **www.autism.org.uk**
Tel: **0207 833 2299**

National Deaf Children's Society
Web: **www.ndcs.org.uk**
Tel: **0808 800 8880**

NDTi
Web: **www.ndti.org.uk**
Email: **hello@ndti.org.uk**
Tel: **01225 255 268**

NHS services
Web: **www.nhs.uk/nhs-services**

Royal Society for Blind Children
Web: **www.rsbc.org.uk**
Email: **connections@rsbc.org.uk**
Tel: **0203 198 0225**

Scope
Web: **www.scope.org.uk**
Email: **helpline@scope.org.uk**
Tel: **0808 800 3333**

Sense
Web: **www.sense.org.uk**
Email: **info@sense.org.uk**
Tel: **0300 330 9272**

SOS!SEN
Web: **sossen.org.uk**
Tel: **020 8538 3731**

Young Epilepsy
Web: **www.youngepilepsy.org.uk**

South East charities

Aspens
Web: **www.aspens.org.uk**
Email: **enquiries@aspens.org.uk**
Tel: **01892 822168**

No Limits
Web: **nolimitshelp.org.uk**
Email: **enquiries@nolimitshelp.org.uk**
Tel: **02380 224224**

Reaching Families
Web: **www.reachingfamilies.org.uk**
Email: **admin@reachingfamilies.org.uk**
Tel: **01903 366360**

Local offer

Bracknell Forest
Web:
bracknellforest.fsd.org.uk/kb5/bracknell/directory/localoffer.page?localofferchannel=0
Email: **fis@bracknell-forest.gov.uk**
Tel: **01344 353133**

Brighton and Hove
Web: **www.brighton-hove.gov.uk/special-educational-needs-and-disabilities**
Email: **sen.team@brighton-hove.gov.uk**
Tel: **01273 293552**

Buckinghamshire
Web: **familyinfo.buckinghamshire.gov.uk/send**
Email:
familyinfo@buckinghamshire.gov.uk
Tel: **01296 383293**

East Sussex
Web: **localoffer.eastsussex.gov.uk**
Email: **localoffer@eastsussex.gov.uk**
Tel: **0345 608 0192**

Hampshire
Web: **fish.hants.gov.uk/kb5/hampshire/directory/localoffer.page?familychannel=6**

Isle of Wight
Web: **familyinfohub.iow.gov.uk/kb5/iow/directory/localoffer.page?familychannel=7**
Email:
familyinformationhub@iow.gov.uk
Tel: **01983 823169**

Kent
Web: **www.kent.gov.uk/education-and-children/special-educational-needs-and-disabilities**
Tel: **03000 419994**

Medway
Web: **www.medway.gov.uk/info/200307/special_educational_needs_and_disabilities_send_information_hub**
Email: **localoffer@medway.gov.uk**

Milton Keynes
Web: **www.mksendlocaloffer.co.uk**
Email:
SENDsupport@milton-keynes.gov.uk

Oxfordshire
Web: **www.oxfordshire.gov.uk/children-and-families/oxfordshire-send-local-offer**
Tel: **01865 815275**

Portsmouth

Web: **portsmouthlocaloffer.org**
Email: **localoffer@portsmouthcc.gov.uk**

Reading

Web: **servicesguide.reading.gov.uk/kb5/reading/directory/family.page?familychannel=3**
Email: **localoffer@reading.gov.uk**
Tel: **0118 937 3777** (option 2)

Slough

Web: **www.sloughfamilyservices.org.uk/kb5/sloughcst/directory/localoffer.page?localofferchannel=0**
Email: **fis@slough.gov.uk**
Tel: **01753 476589**

Southampton

Web: **www.southampton.gov.uk/schools-learning/send-local-offer**

Surrey

Web: **www.surreycc.gov.uk/children/support-and-advice/local-offer**
Email: **localoffer@surreycc.gov.uk**
Tel: **0300 200 1015**

West Berkshire

Web: **www.westberks.gov.uk/article/42837/Special-Educational-Needs-and-Disability-SEND-Local-Offer**
Email: **fis@westberks.gov.uk**
Tel: **01635 503100**

West Sussex

Web:
www.westsussex.gov.uk/local-offer
Email: **localoffer@westsussex.gov.uk**
Tel: **01243 777807**

Windsor and Maidenhead

Web: **rbwm.afcinfo.org.uk/local_offer**

Wokingham

Web: **www.wokingham.gov.uk/children-families-and-young-people/send-local-offer**
Tel: **0118 974 6000**

SENDIASS (Information Advice and Support Service)

Bracknell Forest

Web: **bracknellforestiass.co.uk**
Email: **iass@bracknell-forest.gov.uk**
Tel: **01344 20354011**

Brighton and Hove

See East Sussex

Buckinghamshire

Web:
www.buckinghamshire.gov.uk/schools-and-learning/bucks-sendias-service
Tel: **01296 383754**

East Sussex

Web: **amazesussex.org.uk/sendiass**
Email: **sendiass@amazesussex.org.uk**
Tel: **01273 772289**

Hampshire

Web: **www.hampshiresendiass.co.uk**
Email:
information@hampshiresendiass.co.uk
Tel: **0808 164 5504**

Isle of Wight
Web: **www.iowsendiass.org.uk**
Email: **info@iowsendiass.org.uk**
Tel: **0808 164 5492**

Kent
Web: **www.iask.org.uk**
Email: **iask@kent.gov.uk**
Tel: **03000 413000**

Medway
Web: **family-action.org.uk/services/medway-sendiass**
Email: **medwaysendias@family-action.org.uk**
Tel: **01634 566303**

Milton Keynes
Web: **www.mksendias.org.uk**
Email: **contact@mksendias.org.uk**
Tel: **01908 254518**

Oxfordshire
Web: **www.sendiass-oxfordshire.org.uk**
Email: **info@sendiass-oxfordshire.org.uk**
Tel: **01865 810516**

Portsmouth
Web: **barnardossendiass.org.uk/portsmouth-sendiass**
Email: **portsmouthSENDIASS@barnardos.org.uk**
Tel: **02393 233656**

Reading
Web: **www.readingiass.org**
Email: **iass@brighterfuturesforchildren.org**
Tel: **0118 937 3421**

Slough
Web: **www.sloughsendiass.org.uk**
Email: **sendiass@slough.gov.uk**
Tel: **01753 690729**

Southampton
Web: **www.southamptonsendiass.info**
Email: **southamptoniass@roseroad.org.uk**
Tel: **0300 303 2677**

Surrey
Web: **www.sendadvicesurrey.org.uk**
Email: **sendadvice@surreycc.gov.uk**
Tel: **01737 737300**

West Berkshire
Web: **westberkssendiass.info**
Email: **westberksiass@roseroad.org.uk**
Tel: **0300 303 2644**

West Sussex
Web: **westsussexsendias.org**
Email: **send.ias@westsussex.gov.uk**
Tel: **0330 222 8555**

Windsor and Maidenhead
Web: **www.ias-rbwm.info**
Email: **ias@rbwm.gov.uk**
Tel: **01628 683182**

Wokingham
Web: **www.sendiasswokingham.org.uk**
Email: **sendiass@wokingham.gov.uk**
Tel: **0118 908 8233**

Glossary

Assess, Plan, Do, Review (APDR): a four-step cycle used in schools to support children with additional needs through ongoing monitoring and adjustment.

Attention Deficit Hyperactive Disorder (ADHD): a condition that impacts focus, self-control and activity levels, often leading to impulsive behaviours.

Child Exploitation and Online Protection (CEOP): a national agency that helps protect children from sexual abuse and online exploitation.

Child and Adolescent Mental Health Services (CAMHS): NHS services that support children and young people with mental health difficulties.

Department for Education (DfE): the UK government department responsible for education, children's services and schools.

Department for Work and Pensions (DWP): the government department responsible for welfare, benefits and pensions.

Disabled Living Allowance (DLA): a benefit for children under 16 who need extra help with personal care or mobility due to a disability.

Disabled Students' Allowance (DSA): a grant to support students in higher education with additional costs related to a disability or learning difficulty.

Early Help Assessment (EHA): a process used to identify the needs and challenges a child or young person may be experiencing across areas like health, education and family life, including physical, cognitive, behavioural, and social-emotional development.

Early Years Foundation Stage (EYFS): the national framework for learning, development and care for children from birth to age five.

Education, Health and Care Needs Assessment (EHCNA): a statutory process that assesses a child's or young person's needs and considers what further provision may be appropriate to support them. The education assessment will cover all four areas of SEND.

Education, Health and Care Plan (EHCP): a legally binding document that outlines a child's or young person's SEND needs. It brings together support from education, health and social care services, detailing the personalised support required to help them succeed and prepare for adulthood, beyond what is typically provided in mainstream settings. The local authority and all services named in the plan are legally obligated to provide the support specified in the EHCP.

Education Other Than at School (EOTAS): when education is arranged in a different way, for example through home tuition, online learning or specialist providers.

Every Child A Talker (ECAT): a programme that supports young children's language and communication development.

Holiday Activities and Food (HAF) programme: a government-funded scheme providing food and activities for children during school holidays.

Integrated Care Board (ICB): an NHS organisation that plans and funds local health services in an area.

Local Authority (LA): your local organisation, responsible for arranging education, health and social care support for children and young people with SEND.

Local Offer (LO): your local authority's online guide showing what SEND services and support are available locally and how to access them.

Local Government & Social Care Ombudsman (LGO or LGSCO): an independent organisation that investigates complaints if the local authority hasn't met its SEND duties properly.

Lasting Power of Attorney (LPA): a legal document allowing someone to make decisions on behalf of another person if they lose mental capacity.

Mental Health Act (MHA): the law in England and Wales that sets out when and how people can be detained and treated for mental health issues.

Multi-Agency Safeguarding Hub (MASH): a team of professionals from different services who share information to protect children at risk.

National Portage Association (NPA): an organisation that provides home-visiting educational support for pre-school children with additional needs.

NHS Continuing Healthcare (CHC): a package of care fully funded by the NHS for people with significant health needs.

NHS Right to Choose (RTC): a policy that allows patients to choose which NHS provider delivers their care.

Obsessive-compulsive disorder (OCD): a mental health condition involving unwanted, repetitive thoughts and behaviours.

Occupational Therapists (OT): health professionals who help people develop or regain skills for daily living and independence.

Peer Early Education Partnership (PEEP): a programme that supports parents and carers to enhance their children's early learning.

Personal Independence Payments (PIP): a benefit for people aged 16 and over who need extra help due to disability or health conditions.

Personal Wheelchair Budget (PWB): NHS funding that gives people more choice and control over the wheelchair they use.

Social Care Occupational Therapist (SCOT): a professional who assesses and supports people's needs in the home and community environment.

Special Educational Needs and Disabilities (SEND): a term for children and young people who require extra support due to learning difficulties or disabilities.

Special Educational Needs and Disabilities Co-ordinator (SENDCO): the school staff member responsible for organising support for pupils with SEND.

Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS): a free, confidential service that gives families impartial advice and support on SEND issues, including rights and processes.

Speech and Language Therapists (SALT): specialists who assess and support children with speech, language, and communication difficulties.

Universal Credit (UC): a monthly benefit payment for people on a low income or out of work, which can include extra amounts to support children, including additional help for disabled children.

We want to hear from you

My Family, Our Needs would like to hear your thoughts on how useful you have found this guide. You can complete an online survey by scanning the following QR code.

DISCLAIMER: The information provided in this guide is correct at the time of publication and is subject to change. We recommend checking **www.gov.uk** and conducting your own research to ensure you have the most current information..

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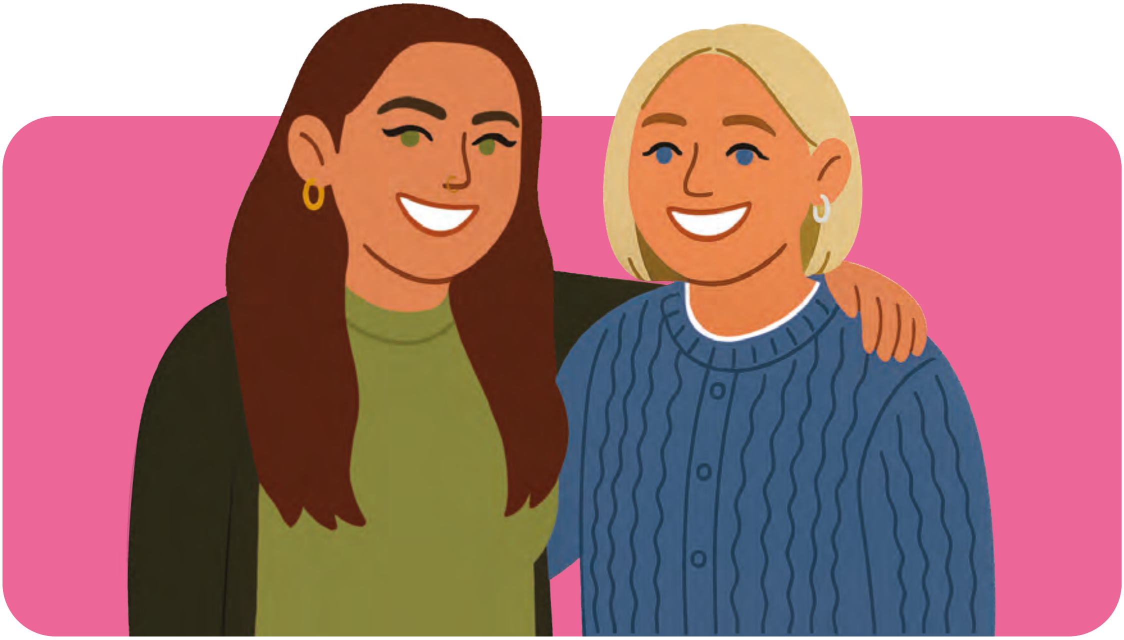

Written and edited by Melissa Rumbold. Designed by Rebecca Mendil.

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Director of Policy and Communications: Jo Dovey.

Director of Sales: David Werthmann.

Director of Creative Operations: Lisa Werthmann.

Sales Manager: Paul O'Callaghan.

Senior Sales Executive: Hannah O'Neill.

Studio Manager: Jamie Harvey.

Lead Designer: Ruth Keating.

Lead Designer – Specialist Titles: Rebecca Mendil.

Graphic Designers: Tyler Smith, Olive Nash.

Author and Editor: Melissa Rumbold.

Lead Editor: Henry Thornton.

Content Editors: Bethany Crow, Aislinn Thompson.

Distribution: Gemma Seaber-Shinn, Jasmine Dalton.

Digital Marketing and Content Manager: Lulu Hines.

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- Ask the Experts
- Real-life blogs
- Practical advice
- Directory

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