



Understanding Chromosome & Gene Disorders

# Education



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## Education guide

The majority of this guide looks specifically at the education system in England.



Children with chromosome or gene disorders often have some degree of learning difficulty. It could be mild and they are able to attend mainstream school with or without support. Or their needs could be more moderate to severe and attendance at a special needs school may be more appropriate and/or beneficial, in order for them to reach their full learning potential. For some children going to school isn't an option and many parents chose to home educate their child(ren). This may be because they are poorly and spend a lot of time in and out of hospital, or it could be because parents had to remove their child from school because the school couldn't meet their child's needs (although every attempt should be made to meet their needs).

This guide has been compiled as a guide for parents whose children have a chromosome or gene disorder. It is not intended to give parents all of the answers, just information and where necessary, signposting to the right agencies/organisations that can offer more specific help and advice.

For those of you whose children are very young, this subject may seem rather daunting. Many of our families are never given the information they need until typical school age is right upon their child.

UNIQUE recommends that parents seek to inform themselves as far in advance as possible; as often the processes to get support for children in school can be lengthy and complicated and the sooner families can start to understand and navigate them, the better their children's outcomes are likely to be.

The SEND Code of Practice which gives guidance on identifying, assessing and providing help for children with special educational needs and disabilities (SEND) will be referred to several times in this guide.

All professionals working with your children should have an **enhanced DBS** (Disclosure and Barring Service) check.

## Education in the United Kingdom

Education in the UK is a 'devolved matter', so England, Wales, Scotland and Northern Ireland all have somewhat different systems. For children with learning difficulties and/or disabilities, the relevant legislation is:

■ **Wales:** Education Act 1996 (legislation on additional needs education is pending)

Website: <http://www.legislation.gov.uk/ukpga/1996/56/contents>

■ **Scotland:** Education (Additional Support for Learning) (Scotland) Acts 2004 & 2009 Education (Scotland) Act 2016

Website: <http://www.legislation.gov.uk/asp/2009/7/contents>

■ **Northern Ireland:** The Education (Northern Ireland) Order 1996 X

Website: <http://www.legislation.gov.uk/nisi/1996/274/contents> and The Special Educational Needs and Disability (NI) Order 2005

Website: <http://www.legislation.gov.uk/nisi/2005/1117/contents>

■ **England:** Children and Families Act 2014 (CAFA 2014)

Website: <http://www.legislation.gov.uk/ukpga/2014/6/contents>

As set out in the [SEND Code of Practice, 2015](#)

Website: <https://tinyurl.com/yc32retd>

All children of compulsory school age must be in education. Most children with special educational needs (SEN) are educated in mainstream schools, with school-level support known as 'SEN Support'. Some children may find their needs are better catered for in specialised units within mainstream schools, or in special needs schools. These units and schools usually only take children with Education, Health and Care Plans (EHCPs). Parents may choose to educate their children 'otherwise than at school'. This is sometimes referred to as Education Otherwise (EO/EOTAS) or Home Education. Children and young people who are home educated are entitled to EHCPs on the same criteria as those educated in school.

Since 2014, the English SEN system covers children and young people aged 0-25. CAFA 2014 states in Section 20 (2):

"A child of compulsory school age or a young person has a learning difficulty or disability if he or she -

(a) has a significantly greater difficulty in learning than the majority of others of the same age, or

(b) has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions" and in Section 36 (8). "(8)The local authority **must** secure an EHC needs assessment for the child or young person if, after having regard to any views expressed and evidence submitted under subsection (7), the authority is of the opinion that- (a) the child or young person **has or may have** special educational needs, and (b) it **may** be necessary for special educational provision to be made for the child or young person in accordance with an EHC plan."

There are pre-school options, so this guide will hopefully help to guide those with young children, so that they can get as much help as possible in their child's early years. Children with special educational needs should get a broad, well-balanced and relevant education, including the foundation stage curriculum (for children aged 3 to 5) or the National Curriculum (for children aged 5 to school leaving age).

## School leaving age - the school leaving age depends on where you live.

With reference to:

Website: <https://www.gov.uk/know-when-you-can-leave-school>

### England

- You can leave school on the last Friday in June if you'll be 16 by the end of the summer holidays
- You must then do one of the following until you're 18:
- Stay in full-time education, for example at a college
- Start an apprenticeship or traineeship
- Spend 20 hours or more a week working or volunteering, while in part-time education or training.

### Wales

- You can leave school on the last Friday in June, as long as you'll be 16 by the end of that school year's summer holidays.

### Scotland

- If you turn 16 between 1 March and 30 September, you can leave school after 31 May of that year.
- If you turn 16 between 1 October and the end of February you can leave at the start of the Christmas holidays in that school year.

### Northern Ireland

- If you turn 16 during the school year (between 1 September and 1 July) you can leave school after 30 June
- If you turn 16 between 2 July and 31 August you can't leave school until 30 June the following year.



## Supporting children and young people with Special Educational Needs and Disabilities (SEND)

The system for supporting children and young people with SEN and Disability changed in England in September 2014. In September 2014 all local councils published a Local Offer setting out what support is available in your area for all children and young people with SEN and disability aged 0-25 years. Statements of special educational needs and Learning Difficulty Assessments (LDA) have been replaced with a single Education, Health and Care (EHC) plan for children and young people with complex needs (In Wales, the Education Act 1996 is still the relevant legislation. Welsh children with SEN still get SSEN (Statements of Special Educational Needs) not EHCps.) The EHC plan places much more emphasis on personal goals and describes the support your child will receive while they are in education or training. Under the new system, which is designed to work better around a family's needs, councils must be able to offer a co-ordinated education health and care plan assessment and issue an EHC plan within 20 weeks where one is needed. Those with an EHC plan also have the legal right to ask for a personal budget, which they will agree with their council. Councils must also make sure there is a source of independent information, advice and support for parents and children and young people with SEN and disabilities. Families will also be able to access new Independent Supporters to help with EHC needs assessments, and transfer from statements to EHC plans. Families must have access to mediation services, so disagreements can be resolved locally. Families still have the right to go to the SEND Tribunal to resolve disputes if they want to do so but must have a certificate from the council to show they have at least considered mediation first. Support for those without EHC plans for those with SEN or disabilities that do not need an EHC plan, will receive SEN support, this replaces School Action and School Action Plus. Schools and nurseries must work with the child's parents or carers when agreeing what support they will provide and what this support will achieve, drawing in additional resources as needed, setting clear targets for progress, and tracking how it is working. Many schools are doing this through working with children and young people to develop one-page profiles which explain what is important to the child or young person, what they want to achieve and how the school will help.

### The National Curriculum for England and Wales

The basic school curriculum includes the 'national curriculum' which covers core subjects like English, maths, history as well as religious education and sex education. The national curriculum is a set of subjects and standards used by primary and secondary schools so children learn the same things. Other types of school like academies and private schools don't have to follow the national curriculum.

*“ Let our children reach their own potential and shine when they reach a milestone, which may seem small to others but to us it's a massive achievement. ”*

Academies must teach a broad and balanced curriculum including English, maths and science. They must also teach religious education. To find out more about the national curriculum, please visit the UK government website: <https://www.gov.uk/national-curriculum>



## Pre-School education

0 to 4 years - At this age your health visitor is your key contact if you have concerns about your child's development.

Your child's early years are a very important time for all areas of their development.

When your health visitor assesses your child at 6-8 months, developmental problems can be picked up. If you have any worries of your own, you should mention this as soon as possible.

If your child is not at nursery or school, you can talk to your doctor or health visitor who will be able to tell you what to do next.

You can also visit your local children's centre for support and advice. Contact your local council offices for details of your nearest children's centre or visit

■ **Gov UK website:** <https://www.gov.uk/find-local-council>

There are different services in Northern Ireland, Scotland and Wales.

If a professional working with your child believes that they may have a disability or a learning difficulty, they can refer them to a [Specialist Child Assessment Centre](#) for an assessment with a range of professionals including therapists, education staff and the home-visiting education service known as Portage.

## ■ National Portage Association

Website: <https://www.portage.org.uk/>

Telephone: 0121 244 1807

Email: [info@portage.org.uk](mailto:info@portage.org.uk)

Portage is a home-visiting educational service for pre-school children with additional support needs and their families. A trained portage worker assesses the child's level of development and provides week by week activities to encourage child development as well as appropriate toys. Portage workers will often be able to recommend suitable activities, services and nurseries and general support to parents of children with special needs. Parents should ask their health visitors to refer them for Portage if they are not offered it, as it is a very valuable service and source of support. Portage is not available in all areas of the UK, but there should be a similar scheme, which would include Early Years Pre-School Play/task Counsellors.

*“Portage was a Godsend to me. My local Portage worker helped me to break down tasks into minute easier steps – it is a method I still practice to this day for my now adult son”*



## Mainstream nursery, playgroup or registered childminder

Playgroups and pre-schools offer mainly sessional care, usually for 2-3 hours a day, either mornings or afternoons, for children aged 2.5 years to 5 years. In some cases, playgroups/pre-schools may have morning and afternoon sessions on the same day. Most playgroups/pre-schools will provide places for between 10 to 20 children. They offer your child a safe, stimulating environment in which to play and learn with other children. Mainstream Playgroups/pre-schools are often run on a voluntary basis by a committee of parents, but are always staffed by a paid, qualified and experienced supervisor with assistant(s). Registration and inspection of pre-schools is carried out by the Office for Standards in Education (OFSTED). At least half of the staff must be trained to work with children. If the playgroup/pre-school is providing early education, it will also be registered with the local authority to receive the Nursery Education Grant for 3 and 4 year olds, more information can be found on the

■ **GOV UK website:** <https://www.gov.uk/help-with-childcare-costs/free-childcare-and-education-for-2-to-4-year-olds>

## Opportunity playgroups

Opportunity playgroups are available in some areas of the UK. If your child has special needs, staff should have the knowledge and skills to give the support needed. You should be offered the opportunity to stay with your child, especially whilst they are settling in. An Opportunity playgroup offers sessions to children unable to access mainstream nursery due to a disability or special educational need (SEN). Some opportunity playgroups also run mother and toddler sessions and sessions for both able and disabled children together. Please contact your local council's family information service or Local Offer website to find out if there is an opportunity playgroup close to you. When your child starts at school or pre-school, therapies may be incorporated into their day by visiting therapists, such as a Speech and Language Therapist (SALT), a Physiotherapist (PT), and Occupational Therapist (OT).

Occasionally these free services can be over-subscribed or lacking on the NHS and many parents of children with a rare chromosome or gene disorder choose to go down the private route in order to obtain extra support for their child. If you can't access these therapies easily, or need additional therapies for your child, all of the therapies mentioned above have private practitioners, the costs of which will vary.





# Children under 5 with SEND

## Identification.

Your child may attend a special needs nursery, or a nursery with a SENCo on site. Initial discussion with parents during home visits will help staff to identify children's needs. During the child's first half term in nursery, staff will observe and monitor the child. Parent consultations in the first term will be used to discuss the child's progress and share any concerns. Where there are concerns, further observations will take place and these will be discussed with the SENCo. Children may join the nursery with previously identified needs. These will be discussed with the parents, and liaison with other professionals may take place.

Depending on the level of need, support will be provided appropriately e.g. 1:1 support. In the Autumn term a meeting with the educational psychologist, SENCo and Head teacher is held where individual children are discussed. The consent of parents will always be sought before discussing a child at this meeting.

### What is a SENCo?

SENCo (Special Educational Needs Co-ordinator).

A SENCO is the main person responsible for the school's SEN policy. All mainstream schools must appoint a teacher to be their SENCo. The SENCo will co-ordinate additional support for students with special educational needs and liaise with their parents, teachers and other professionals who work with them.

## Provision

Once a particular child's needs have been identified, discussions will take place with the SENCO in order to identify the best way of supporting the child. Staff will discuss strategies to help particular children as part of their on-going planning. Support for individual children will be given during activities chosen by the child if possible, but there may be times when specific activities are introduced to the child in order to help development in a particular area. Additional staff may be employed to support individual children with specific and significant needs. These children will generally be those who are undergoing a multi professional assessment of their needs. The SENCO will liaise with individual key carers to ensure that each child who has been identified as having additional needs has a plan of action. The SENCO or Key Carer will liaise with other agencies to support children and identify the next steps in their learning.

## Early Years Planning and Review Meetings (EYPARM)

Early Years PARM Meetings are held each term and bring together a wide range of professionals from across the locality. Professionals refer children with identified needs and these children are discussed to ensure that they are receiving the appropriate support and provision. This panel will decide on whether to recommend that an educational psychologist visits a child with a view to recommending them for statutory assessment.

## What is an Educational Psychologist and what do they do?

Educational psychologists work in a variety of different ways to address the problems experienced by children and young people in education. They have a central role in the statutory assessment for children with special educational needs (SEN). They work directly with children and young people individually, or in groups, and with a wide range of other professionals. Educational psychologists promote the learning of all children and young people. They offer consultation, advice and training on how early years settings and schools and parents/carers might help children and young people to learn effectively, and to make the most out of their education. Your child's early education setting or school may ask an educational psychologist for advice about your child. You will always be informed of any discussions that take place. The educational psychologist will listen to the early years setting's or school's concerns about your child and details of what the school has already done. The educational psychologist will work with the teachers to plan the best way to help your child progress.

## How to get support for children aged 0-5 with additional needs and/or a disability.

### Requesting support

When a child has complex needs and/or multiple disabilities there may be a large number of people providing support and services for them.

**The Early Support service** brings together parents, carers and practitioners from health, education, social care and the voluntary sector to:

- Co-ordinate services as early as possible through a key-working approach
- Make sure everyone involved is aware of the overall needs of the child and the family
- Try to reduce the need for parents or carers to explain their situation more than once.

The Early Support service offers support to families from pre-birth to the end of the child's first term in school reception year. They support children who:

- Have complex or multiple needs relating to their learning or physical development, that are persistent and ongoing
- Have a County Council boundary home address (including looked after children)
- Is receiving, is eligible for, or is about to receive, multi-agency input from two or more targeted services, in addition to a Paediatrician, the Health Visiting Team or GP.

*“I went through this process last year for my 3-year-old son. It was quite stressful, but I think that was more my desperation as a parent to get one, as I had my heart set on him attending a special needs nursery after 2 failed attempts at mainstream. I got in touch with parent partnership (now IASS) who gave me the number for core assets (<https://www.corechildrensservices.co.uk/>) and had a lovely lady from there go through the process with me, coming to my home to help fill out paperwork and also came to the draft plan meeting with me which helped a lot.”*

## Visit an Early Years hub

Early Years hubs make it easier for families with children under 5 with SEND to access advice, guidance, services and activities at a convenient location. Each hub hosts a 'Play and Learn Plus' parent and child group full of opportunities for your child to explore and learn through play and the chance for you to meet other parents and carers. Sensory play equipment is available during the sessions and many have a sensory room that you can use. Staff can help you with information about local services and activities for parents of children with disabilities or additional needs. You can access specialist toys through their sensory toy libraries and get advice on benefits that you may be entitled to. In some hubs, specialist therapies offered by health partners may be available. Some have hearing loops and all are wheelchair accessible. Hubs are usually located within Children and Family Centres, details of which can be found on your county council website or Local offer website under 'early support'. An Educational Psychologist visit is part of the statutory assessment process and is only a required step *after* the decision to assess, not before. A decision to request assessment should not be delayed because an Educational Psychologist has not seen the child.



*“We were the first in Herefordshire to go through the new ECHP process so I was very apprehensive, but it was totally straightforward. The process started 4 Sept 2014, final plan approved by 4 Jan 2015 and everything in place for when T. started Reception in Sept 2015. It helped that everyone agreed that mainstream with 1:1 was the way to go and with the amount of hours needed. The process was very clear throughout. We've recently had the one-year review and necessary amendments are already in place.”*

*“ Try not to make assumptions about what school would be right for your child at an early age, either by discounting mainstream or special school and don't feel that you should be constrained by what your LA's say to you. e.g. the LA tells you that your child could only go to x, y or z.....*

*– An Educational psychologist.”*

## Choice of school

All children in England between the ages of 5 and 18 are entitled to a free place at a state school. Most state schools follow the national curriculum.

**Mainstream School** - A mainstream school is your typical village or town primary or secondary school.

**Mainstream with special support unit attached** – There are some mainstream schools that might have a specialist unit attached. This might be for children that have for example: a hearing or speech impairment.

**Special Needs School**- A special needs school is one that has been designed to meet the needs of children who need more help with their learning than can be provided in a mainstream school setting. It is a school that is for children with an EHCP. Some special needs schools have a specialist nursery assessment unit which can take children from as young as 2 years old; but just because this unit maybe attached to a special needs school, it doesn't automatically follow that your child will have to go into the school it is attached to. In some circumstance's students are able to attend both mainstream and special needs school during the same week. This may be referred to as integration or inclusion. Choosing the right school for a child with a rare chromosome or gene disorder is important and can be tricky. It involves weighing up the merits and compromises of the many different options. Your choice depends on many factors not just /or necessarily the degree of learning difficulties. Other factors to take into consideration include:

- The quality of local special and mainstream schools on offer (parents of very delayed children may prefer a mainstream school if there isn't an appropriate special school nearby)
- Parental involvement so make sure the child should be provided with the support that they need irrespective of setting
- Feelings of the children (some may be upset by not being able to keep up with their peers, while others may not care)
- Family circumstances (such as whether you want to educate your children in the same setting or, deliberately keep their school day separate).

Choice of schools will also depend on parents' greatest areas of concern, for example some may want to focus on a unit or special school specialising in communication skills, or a school that specialises in developing gross motor

skills, while others may want a school with strengths in art or music. Mainstream schools which were unwelcoming and inexperienced a few years ago, may realise that including children with SEN brings great benefit to the education of all of their children and that it is not so difficult to manage. Meanwhile many special needs schools are gradually changing their intake because children with milder needs are going into mainstream and because of the increase in children being diagnosed with autism.

## Mainstream

An advantage of going into mainstream education is that children can benefit from going to school with their local peers (brothers, sisters, neighbours and become known and integrated in their local communities). They may also benefit from the stimulation and role modelling of typically developing children; they will be exposed to hearing lots of speaking children modelling normal speech. They may receive higher levels of 1:1 therapy (speech and language, occupational therapy, physio) because the services have to be delivered to the children individually in mainstream settings. Schools may have fewer preconceptions about what maximum levels children may reach academically and may therefore have higher aspirations for them. The disadvantages tend to be that by definition teachers and staff are not trained or very experienced or specialised in special needs; this may result in inappropriate approaches to behaviour management and discipline, and not knowing how to teach in the appropriate manner. Children with learning support assistants often end up doing much of their learning one-to-one with the adult rather than through proper integration in the class. Children may become overly dependent on their support assistants and less independent as a result. Some children may find a normal school environment too challenging, e.g. because of stairs, noise levels, higher class numbers and the sheer number of children in the school; children may find it difficult to make friends or integrate into a social group if they are one of only a few children with a complex disorder. If looking at mainstream schools, it is important to bear in mind that the best school for a typically developing child may not be the best for a child with special needs. An emphasis on a nurturing, inclusive and welcoming environment, rather than on outstanding league table results, may provide a more accommodating environment.

*“ Kids.org were amazing, helping us through the process, we didn't get help from Nursery because they thought that because my daughter had additional funding she would be fine at School. So we applied ourselves, not taking no for an answer (haha). I am glad we pushed it. Kids came to our house and checked all our paperwork. We successfully got the EHCP first time we put forward a 3000 word parental view which I think helped. It took us 20 weeks in total, although our local council were running behind on deadlines for EHCP and to make it in the 20-week deadline. They sped through the meetings and agreed to all the amendments we wanted, which worked massively in our favour. ”*

## Special Needs School:

The advantages may include:

- Specially trained staff
- Adapted facilities
- Onsite therapies
- A natural peer group of similar children
- Expertise in specific areas  
e.g. alternative means of communication or physiotherapy
- More focus on learning
- Independence and life skills
- A less competitive and not exam-driven academic environment.

The disadvantages may include lower aspirations for the children and not pushing them to their maximum potential. Special needs schools can be further from home and can involve long journeys with little chance for children and families to socialise outside school. Parents tend to feel less “different” in a special needs school but may have less opportunity to get involved in school life as most children are transported to school every day. When looking at special needs schools bear in mind that many take a wider range of children than their strict legal description suggests e.g. schools for dyslexia may take children with more complex needs as well. Also, a child with a primary diagnosis of learning difficulties may benefit from an environment with a different official specialisation e.g. autism or communication skills. The only way to decide is to visit as many different schools as possible and talk to other parents in similar situations and gather recommendations from professionals.

*“ Having first applied for an EHCP in May we've just been told my daughter can start reception at our choice of specialist school in September. Took hundreds of hours of time but so worth it all, knowing she got in the best place for her! ”*

## What if the school you think best, will not take your child?

Your local state mainstream schools should put you virtually top of this list of admissions criteria if you select them. Distance from school and church references should not apply, so you may consider schools that a typically developing child would not get into, e.g. because you are out of the catchment area. The school can reject your child if taking him or her would be incompatible with the efficient education of the other children (e.g. dangerous behaviour) or because they could not meet their needs (e.g. unable to make modifications to the building). These thresholds are set very high and schools are expected to make ‘reasonable adjustments’ to accommodate children with special needs, whether it is installing ramps, acoustic insulation to classrooms, or accommodating a learning support assistant in the classroom. Inconvenience and lack of will to include your child or lack of experience are not acceptable reasons! Schools should obtain necessary training for staff at the school. Parents need to ensure that the child’s EHC plan covers the funding for the right number of hours of 1:1 support in school, and the right level speech and language, educational psychology, and occupational therapy services as appropriate.



Funding for IT and physical adaptations to the school should be obtained from the school's or the local authorities budget. If you choose to opt for a special needs school, it is a question of finding a school that can meet your child's needs and has the capacity to take your child - as more and more schools are getting full, or don't have the funding to take on more children. Many children go to special schools outside their local authority area and you may need to argue the case. For a place at a school which involves long and expensive transport, or at an independent school, you may need to push hard and it may help to use a parent or advocacy service (page 37).

## Residential special schools

Most children with an EHCP attend a local school. Others may find they need more support from a mainstream school with a special unit attached or a specialist needs school. Your child may have to travel further to attend such a school. However, if your child has more complex needs or there is no suitable local provision, you may feel that they require a different type of learning environment, such as a residential special school. For many parents of a child with a disability, choosing a residential school is a daunting and often emotional task. There are some specialised residential schools throughout the country, however there aren't many of them and often you might find there is no suitable school close to where you live. These schools specialise in a variety of different disabilities, so you should find out which ones would be the most relevant for your child.

## How to find out about residential special schools

If your child has an EHCP, the Local Education Authority must provide you with details of all primary and secondary schools in the area, including independent and special schools. There is some useful information to be found here:

■ **The Good schools guide website:**

<https://www.goodschoolsguide.co.uk/special-educational-needs/schools/residential-special-schools>

## Find a school

■ **Website** <https://www.specialneedsuk.org/> has a good search facility for a selection of day and residential special schools. You can also search for a school by a particular need here:

■ **Website:** <https://www.specialneedsuk.org/findaschool.asp>

Most schools will have a prospectus (brochure) outlining their aims and beliefs and what type of care they provide. This will give you a general idea of what they offer. You can check out their Ofsted reports which should be available to view online at

■ **Ofsted Website:** <https://reports.ofsted.gov.uk/>

You should arrange to visit the school and speak to the teachers and students if at all possible. There are after school and holiday clubs which may be run by the school, but these aren't available at all schools. Check with the school or local family information service for your nearest.

## Education, Health and Care Plan

An Education, Health and Care plan (EHC plan) describes your child's special educational needs (SEN) and what help they will need to meet them. An EHC plan also includes any health and care provision they need. It is a legal document written by the local authority and is used for children and young people with high support needs.

EHC plans are for children and young people who need a high level of support. The plans can start from a child's birth and continue into further education and training.

### Special educational needs, disability and areas of need

The Special Educational Needs and Disability Code of Practice (2015) defines special educational needs as follows:

"A child or young person has SEN if they have a learning difficulty which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- Has a significantly greater difficulty in learning than the majority of others of the same age
- Has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream-post 16 institutions."

For children aged two or more, special educational provision is education or training provision that is additional to, or different from, that generally made for other children of the same age. For a child under the age of two, special educational provision means education provision of any kind. A child under compulsory school age has special educational needs if he or she is likely to fall within the definition shown above when they reach compulsory school age or would do so if special educational provision were not made available for them.

Children's special educational needs are generally thought of in the following four broad areas of need and support

- Communication and interaction
- Cognition and learning
- Social, emotional and mental health, and
- Sensory and/or physical needs.

There is often an overlap between disability and special educational needs. A child can be defined as having special educational needs (SEN) or having special educational needs and disabilities (SEND).

### Who needs an EHC plan?

EHC plans are for children and young people who have a special educational need or disability that cannot be met by the support that is usually available at their school or college. Most children and young people with special education needs will have help given to them without the need for an EHC plan.

This is called SEN Support. The purpose of SEN Support is to help children achieve the outcomes or learning objectives that have been set for them. Some children and young people may not make the progress expected of them even with this help. When this happens the Local Authority should carry out an EHC needs assessment. A few children and young people have such significant difficulties that an EHC assessment should not be delayed. You or your child's school can ask the local authority to make an EHC needs assessment. When this assessment is finished, the local authority must decide whether to issue an EHC plan.

The [SEND Code of Practice](#) is secondary to the legislation and the statutory threshold for doing an EHC needs assessment is:

- Whether the child or young person has or may have special educational needs (SEN) and
- Whether they may need special educational provision to be made through an EHC plan.

If the answer to both of these questions is yes, the LA must carry out an EHC needs assessment.

This test is set out in the law (section 36(8) of the Children and Families Act 2014). These are the only questions the LA should be asking when considering whether or not to carry out an EHC needs assessment.

The considerations about progress are examples of the types of evidence that can show needs, but it does not mean that an EHCP cannot be applied for or granted until a child has demonstrated a lack of progress. (LA's often suggest that a child 'must' be delayed by X number of years before they are eligible for an assessment, which can delay EHCP provision).

The [SEND Code of Practice](#) states: *"In considering whether an EHC needs assessment is necessary, the local authority should consider whether there is evidence that despite the early years providers, school or post-16 institution having taken relevant and purposeful action to identify, assess and meet the special educational needs of the child or young person, the child or young person has not made expected progress (9.14)."*

## Local Offer

Every Local Authority is required to publish information about available services both in and outside their local area for children and young people from birth to 25 years, who have special educational needs and/or disabilities (SEND). This is known as the 'Local Offer'.

It has two key purposes:

1. Clear, comprehensive and accessible information about the provision available. Making provision more responsive to local needs by directly involving children and young people, parents carers and service providers in its development and review.
2. It gives parents and carers guidance on how to access a range of services, e.g. location, criteria, accessibility and not simply be a directory of existing services.

The Local Offer has a membership base that includes -

- Charities offering sporting, leisure and social activities
- Dyslexia specialist teachers
- Holistic therapy and mindfulness practitioners
- SEND consultancy service
- SEND consultants and consultancy service
- Service children support networks
- Social, sporting and leisure services
- Therapeutic riding centres
- Visual impairment practitioners
- Wraparound care services.



All of these services form part of the Local Offer. They operate either locally, regionally or nationally. Some have a number of branches across the country. The SEND reforms are already having a significant impact on the way services are chosen and commissioned to deliver support on behalf of children and young people (0 - 25 years).

## What does an EHC plan include?

The [SEND Code of Practice](#) states that the EHC plans should be based on decisions made openly involving parents and where appropriate the child or young person. They should:

- Describe what the child or young person can do
- Be clear, concise, understandable and accessible
- Consider how best to achieve the outcomes for the child or young person. They must take into account the evidence from the EHC needs assessment
- Specify clear outcomes
- Consider alternative ways of providing support if a parent or young person wishes it. This could include having a Personal Budget
- Show how education, health and care provision will be co-ordinated
- Be forward looking – for example: anticipating, planning and commissioning for important transition points in a child or young person's life
- Describe how informal support as well as formal support from statutory agencies can help in achieving agreed outcomes.

There is a full list of principles and requirements in the [SEND Code of Practice](#) section 9.61.

Every EHC plan must include at least 12 sections, but each local authority can decide how to set these out. The sections are:

- The views, interests and aspirations of you and your child or the young person
- Your child's or young person's special educational needs
- Health needs related to their SEN or to a disability
- Social Care needs related to their SEN or to a disability
- Planned outcomes for your child or the young person
- Special education provision. Provision must be specified for each and every need shown in section B.
- Any health provision requires that is related to their SEN or to a disability
- H1. Any social care provision that must be made for your child or young person under 18.
- H2. Any other social care provision required that is related to their SEN or to a disability
- The name and type of school, maintained nursery school, post-16 institution or other institution to be attended.
- Details of how any personal budget will support particular outcomes and the provision it will be used for
- The advice and information gathered during the EHC needs assessment.

Where the child or young person is in or beyond year 9, the EHC plan must also include the provision required by your child or young person, to help prepare for adulthood and independent living.

You can read the full list of what must be included in each section in the [SEND Code of Practice](#) sections 9.62 and 9.63.

*“ I went through the EHC process with my youngest and found the whole process very simple and professional compared to the statement process I went through with my twins. I think the EHC was quite straightforward, but I think it probably helped that J. was already in a specialist nursery, so it was easier to get the evidence needed for the EHCP in order for him to be able to make the transition into a speech and language school. Having a specific need (speech and language) also made the process easier, whereas the twins have more global needs and the council refused to acknowledge their chromosome deletion, as they knew little about it, so their statement was only awarded after an appeal and with the help of families in focus and a letter from Unique.”*

## How will I be involved?

The [SEND Code of Practice](#) states: *"Local Authorities must consult the child and the child's parent or the young person throughout the process of assessment and production of an EHC plan. (9.21) and reviews must be undertaken in partnership with the child and their parent or the young person, and must take account of their view, wishes and feelings, including their right to request a Personal Budget. (9.168)"*

Your views, and your child's views are really important. The local authority, school or college should help you take part and involve you in decision making. If you would like to do this, please contact your local Parent information service (IAS) for impartial information and support. They can also give you information on other sources of help, and on what to do if you do not feel that you have been heard or listened to.

## Will there be a review of the EHC plan?

The local authority must review the EHC plan at least every 12 months. This must be done in partnership with you and your child or the young person, and must take account of your views, wishes and feelings.

The local authority must decide whether to keep the plan as it is, make changes or cease to maintain it within four weeks of the review meeting. You have a right of appeal if the local authority proposes to cease the EHC plan.

For some young people an EHC plan will continue until they are 25.

However, the plan will stop if the young person:

- Goes to university
- Gets a job
- Tells their local authority they no longer want their EHC plan, or
- No longer needs special help and the local authority decides that the EHC plan should cease.

*" We have had I's EHCP for a year now. I found the process very simple and straight forward. I thought that it would be a struggle and a fight but actually it was far from it. We are about to start the process of moving to another county, as my husband is in the army and we have been posted. "*

## Where does the funding come from?

The local authority is responsible for ensuring that all the needs set out in the EHC plan are met and that the provision is made. Funding for EHC plans usually comes from a number of sources. For children in mainstream school, some of the funding comes from the school. The local authority may top up this funding from their 'High Needs Block'. Special needs schools have a standard amount of funding for each student. This can also be 'topped up' with Element 3 funding when necessary. For young people in 6<sup>th</sup> forms or attending college, some of the funding will come from the college budget. This may be topped up by the local authority, if the amount of funding needed is more than the 'nationally prescribed threshold'. This is an amount of money that is decided on each year. All young people with an EHC plan and all parents of children with an EHC plan can ask for a Personal Budget.



The [SEND Code of Practice](#) states: “A *Personal Budget* is an amount of money identified by the local authority to deliver provisions set out in an EHC plan where the parent or young person is involved in securing that provision. (9.95). Sections 9.110 to 9.118 of the SEND Code of Practice tell you more about what can be included in a Personal Budget.”

### **What can I do if I am not happy about the EHC plan?**

The first step is to contact the school, college or local authority to discuss your concerns.

### **What happens if I move to another local authority area?**

If you plan to move to another local authority area, you should contact the ‘old’ and the ‘new’ local authorities, so the support specified in the EHC plan will be in place. The ‘new’ authority will amend the plan and name the new school or college. The ‘old’ local authority must transfer the EHC plan on the day of the move, as long as it has had 15 working days’ notice.

### **Where can I get more information, advice or support?**

You can read about EHC plans in Chapter 9 of the SEND Code of Practice on your Local Offer website or IASS website.

*“ I applied for an EHC assessment in September 2014 it was declined. I went to Mediation and then the SEND Tribunal - for my daughter to be reassessed, which I won. It is all a mess as I am back to mediation again. My daughter's chromosome deletion was also ignored during the reassessment from Health. ”*

## **EHC Needs Assessment**

The Education, Health and Care needs assessment (EHC Needs Assessment), which used to be called a ‘statutory assessment’ covers:

- Children in early years setting
- Children of compulsory school age
- Young people aged 16-25 in college or further education

### **What is an EHC needs assessment?**

An EHC needs assessment is a detailed look at a child/young person’s special educational needs (SEN) and the support he or she may need in order to learn. Local authorities are responsible for carrying out EHC needs assessments under the Children and Families Act 2014.

The needs assessment brings together information about:

- What your child can and cannot do
- The special help they need

It includes information from:

- You
- Your child/young person
- The early years setting, school or post 16 provider
- Other professionals who work with or support your child/young person.

The assessment is to see if your child needs an EHCP.



### When is an EHC needs assessment necessary?

The school, early years setting or post 16 provider can often give your child help through SEN support. This means that the school makes additional or different provision to meet their needs. Sometimes other professionals will give advice or support to help your child learn. Some children need more intensive and specialist help. Your child does not need to have made progress before an EHCA can be requested. The assessment criteria is 'has or \*may have\* SEN and \*may\* need an EHCP.

The [SEND Code of Practice](#) states: *"In considering where an EHC needs assessment is necessary, the local authority should consider whether there is evidence that despite the early years provider, school or post-16 institution having taken relevant and purposeful action to identify, assess and meet the special educational needs of the child or young person, the child or young person has not made expected progress. (9.14)"*

### Who can ask for an EHC needs assessment?

- A parent-by writing to the local authority
- A young person over the age of 16 but under the age of 25
- The early years setting, school or post 16 provider, but only after talking with you first.
- Other people, such as a doctor or health visitor, can tell the local authority that they think your child needs an assessment.

### What happens when the local authority gets a request for an EHC needs assessment?

As soon as the local authority gets a request for an EHC needs assessment they must tell you about it. The local authority has up to six weeks to decide whether to make a needs assessment. During this time it may ask you, the school and other professionals for information. It will look at all the information and must then tell you whether it has decided:

To start the EHC needs assessment immediately or that an EHC needs assessment is not necessary.

## What happens if the local authority decides that an EHC needs assessment is not necessary?

The local authority must tell you why it thinks that an EHC needs assessment is not needed. It must also tell you about:

- Your right to appeal
- Independent disagreement resolution and mediation
- How to get further information, advice or support

The [SEND Code of Practice](#) states: *"Local authorities must consult the child and the child's parent or the young person throughout the process of assessment and production of an EHC plan. They should also involve the child as far as possible in this process. The needs of the individual child and young person should sit at the heart of the assessment and planning process. (9.21)"*

If your child has a vision or hearing impairment the local authority must also seek information and advice from a suitably qualified teacher.

The local authority should also try to find out your child's views. You, the school and other professionals may be able to help with this. If you think your child needs someone to help them give their views you can ask your local Information, Advice and Support Service for more information about this. You will have the chance to discuss your child with everyone involved in the needs assessment and you will receive a copy of all the reports when the needs assessment is finished. If you want information advice or support during the EHC needs assessment contact your local IASS.

### **Information, Advice & Support Service (IASS)**

IASS have a duty to provide information, advice and support to disabled children and young people, and those with SEN, and their parents. There should be an IASS Service in every local authority. Find your nearest one here:

<https://councilfordisabledchildren.org.uk/information-advice-and-support-services-network/find-your-local-ias-service>

This can include having an independent supporter to help you. You can find out more about advice, and information for EHC needs assessments in the SEND Code of practice sections 9.45-9.52.

The IPSEA (Independent Parental Special Educational Advice) website (see page 27) offers definitive advice for SEN in England.

## What if some of this advice is already available?

Sometimes advice and information is already available because other professionals have been working with your child.



The **SEND Code of Practice** states: “ the local authority must not seek further advice if such advice has already been provided for any purpose and the person providing the advice, the local authority and the child’s parent or the young person are all satisfied that it is sufficient for the assessment process. In making this decision, the local authority and the person providing the advice should ensure the advice remains current (9.47) ”

Conversely, if you think some of the advice is insufficient, you can request that the LA seek more, e.g. any reports that are out of date, and more than 12 months old; are likely to be insufficient.

### **When does the EHC needs assessment end?**

Once the local authority has all the information and advice it must decide whether your child needs an EHCP. Sometimes the local authority will decide that your child has special educational needs that can be met through ‘SEN Support’. If this is the case the local authority must tell you of its decision within 16 weeks of receiving a request for an EHC needs

assessment. The local authority must also tell you about your right of appeal. If the local authority decides an EHC plan is necessary, it must first write a draft plan. It will send you the draft EHC plan and copies of the reports so that you can read it all. You should check that everything you think is important has been included and that you agree with the outcomes and the proposed provision. The local authority will also ask you which school you prefer your child to go to. You have 15 days to make comments, to ask for a meeting or accept the draft plan. Note that if you do not reply within 15 days the local authority may assume that you agree with the draft plan, so if you feel you need more time to consider options, please let the local authority know.

### **Can I choose any school?**

The **SEND Code of Practice** states that local authorities must consider your preference as long as:

- It would be suitable for the age, ability, aptitude or SEN of the child or young person, or
- The attendance of the child or young person there would be incompatible with the efficient education of others, or the efficient use of resources. (9.79).

“ We started as the L.A’s Guinea pig back in 2014 and were first to go through the process. He had his first annual review and finalised the first amendment. A very clear process in our borough and included me all the way. ”

The last stage is for the local authority to send you the final EHC plan. If you are still unhappy with the plan or cannot agree with the local authority on a school, you have a right to go to mediation and/or appeal. If you need help at any stage you can contact your local IASS.

**How long does all this take?**

Sometimes this timescale can be different. See the [SEND Code of Practice](#) Section 9.42.

The local authority receives a request for an EHC needs assessment. The authority must tell parents about this request.	This is the start date
The local authority decided whether an EHC needs assessment is needed. The authority must tell parents about its decision.	Within six weeks of the start date.
The EHC needs assessment takes place.	This starts as soon as the decision is made.

Either

Or

The local authority tells the parents of the decision not to issue an EHC plan	Within 16 weeks of the start date
--	-----------------------------------

The local authority sends a draft EHC plan to parents.	Within 16 weeks of the start date.
Parents must respond to the draft EHC plan. They can: <ul style="list-style-type: none"><li>■ Agree that the draft is accurate</li><li>■ Ask for changes</li><li>■ Ask for a meeting</li><li>■ Parents also state a preference for a school or early years setting.</li></ul>	Within 15 days of receiving the draft EHC plan.
The local authority consults with the school or early years setting.	Within 15 days of parents response to the draft EHC plan.
The local authority issues the final EHC plan.	Within 20 weeks of the start date.



## What if I do not agree with the local authority about the EHC needs assessment or the EHC plan?

At any stage you can ask to talk to a member of the local authority's staff. This will usually be the person named in the letter the local authority sends to you when it receives a request for an EHC needs assessment.

You also have a right to request independent disagreement resolution and in some circumstances, mediation. You can find out more about disagreement resolution and mediation on the Local Offer website and in the [SEND Code of Practice](#) Chapter 9.

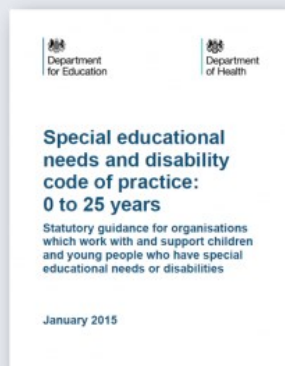
## Where can I get more information, advice or support?

The [SEND Code of Practice](#) (see page 4 for website) gives guidance on identifying, assessing and providing help for children with special educational needs and disabilities (SEND) to:

- 6<sup>th</sup> Forms and FE colleges
- Clinical Commissioning Groups (CCG's)
- Independent special schools/providers
- Early Years Providers
- Local Authorities
- NHS England
- NHS Trusts
- Primary/Secondary schools – including academies and free schools
- Pupil referral units/alternative providers

This guide is for many people, including (amongst others):

- Parents/carers, young people and their advocates
- Teachers/SENCOs/lecturers (both in mainstream/special schools or colleges)
- Local authority officers (dealing with 'education' or 'care')
- Healthcare professionals (e.g. therapists, psychologists, doctors)
- Anyone involved in complaints/appeals/dispute resolution.



### UK Government website

[www.gov.uk/government/publications/send-code-of-practice-0-to-25](http://www.gov.uk/government/publications/send-code-of-practice-0-to-25)

Other SEND guides are also available on the Government website:  
<https://www.gov.uk/topic/schools-colleges-childrens-services/special-educational-needs-disabilities>

*“ I'd recommend that people get an independent supporter to guide them through the process. ”*



■ **IPSEA** Website: [www.ipsea.org.uk/](http://www.ipsea.org.uk/)

Telephone: [01799 582030](tel:01799582030) (Monday to Friday, 9am-5pm)

IPSEA is a registered charity offering free and independent advice to parents of children with special educational needs in England and Wales on:

- Local authorities' legal duties to assess and provide for children with special educational needs
- Exclusions of children with special needs/disabilities
- Actions or inaction by local authorities and/or schools which discriminate against children with disabilities
- Online resources
- Online information service
- Advice line
- Tribunal helpline
- Tribunal support service

IPSEA is a volunteer-based organisation and many of the volunteers providing telephone advice and Tribunal support are themselves parents of children with special educational needs who have been helped by IPSEA.

Disabled Children: **a legal handbook**, is an authoritative yet accessible guide to the legal rights of disabled children and their families in England.

■ Website: <https://tinyurl.com/mrsew8kc>

### Technology at school

For many children with communication problems, technology in schools/at home, can help them to learn and communicate in their education. AAC devices and computers, iPads and tablets with specific programmes for example, are now widely used in schools. For more information, please see our separate guide on communication, which is available to download from our website <https://www.rarechromo.org/practical-guides-for-families>



# Transport to and from school

Free transport

With reference to Gov Uk website:

<https://www.gov.uk/free-school-transport>

It states.....

Your children may be able to get free transport to school, depending on how far the walk is and any special needs they have. All children between 5 and 16 qualify for free school transport if they go to their nearest suitable school and live at least:

⇒ 2 miles from the school if they're under 8

⇒ 3 miles from the school if they're 8 or older.

Find details on free school transport from your local council. If there's no safe walking route, they must be given free transport, however far from school they live. Contact your local council if you think that the walk to school isn't safe. Families on low incomes - If you get the maximum Working Tax Credit or your children are entitled to free school meals, they'll get free school transport if they're:

- Aged 8 to 11 and the school's at least 2 miles away
- Aged 11 to 16 and the school's 2 to 6 miles away - as long as there aren't 3 or more suitable schools nearer to home
- Aged 11 to 16 and the school's 2 to 15 miles away - if it's their nearest school preferred on the grounds of religion or belief.

## HOME EDUCATION

Children with special educational needs have an equal right to be educated at home. Where a child has an Education Health Care Plan (EHCP) and is educated otherwise than at school, either the parent makes the special educational provision, or it is arranged and funded by the local authority. It is extremely rare for local authorities to provide therapies or support (including SALT or OT) once a child is home educated, as parents are deemed to have opted out. In order to get a personal budget and direct payments for a home educated child with SEN it is necessary

- a) for the child to have an EHCP and
- b) for the local authority to agree the funding by naming home education in the plan (rather than naming a type of school and adding that parents have made their own arrangements). A handful of Direct Payments for home education were offered during the Pathfinder trials for the new SEN system, although on closer inspection these tended to be where a child was on roll at a special school but not attending - i.e. where the school budget was delegated - or where disabled child short breaks funding was used. For some children with a chromosome or gene disorder going to school may be difficult. This could be because of their general overall health, meaning long or frequent hospital stays or it could be that the school environment is too noisy and they cannot cope in that situation. You may feel that your child is not getting the right education to meet their needs. Legally, you do not need to have any teaching qualifications to home educate your child. You have



the right to educate your child at home as per the 'Education Otherwise Than As School' provisions of the Education Act.

You can educate your child at home, full or part-time (home educating) - but tell the school and your local council if you are taking them out of school. As a parent, you must make sure your child receives an education from the age of 5 but you don't have to follow the national curriculum. If the council wants to check on your child's education, they can make an informal enquiry to make sure they are getting a suitable education. If the council thinks your child isn't receiving a suitable education, they might serve a school attendance order. You can get help with home education from your local council.

**Telling the school** - If you are taking your child out of school you must write to the head teacher. You can ask the school to teach your child part-time, but the school doesn't have to accept your request.



*“ I took my son out of school because the school could not cope with him and he was receiving a very poor education. He learns things that I think will benefit him as an adult and I follow his lead and interests in providing other learning opportunities. We often learn together and both enjoy getting out into the local community. His education is truly personalised and he is much calmer and happier learning in a home environment. We have joined a local home education group where there are opportunities to socialise almost every day. It can be hard work, but he has learned so much at home and tried activities that he would never have had the chance to do at school. ”*

The legal aspects of Home educating in the UK are covered very well on the following websites:

- Home education SEN guidance (England) <http://ehe-sen.org.uk/>
- Home education <http://www.home-education.org.uk/>  
General information on all aspects of home education in the UK
- Ed. Yourself (England and Wales) <http://edyourself.org/>

## ■ HE-Special-UK

Website: <http://www.he-special.org.uk/>

A supportive online forum for all those either considering/or home educating their children with special educational needs

## ■ Education otherwise (UK)

Website: <https://educationotherwise.org/>

provides information and resources for home educating families and those considering home education for the first time, including guidance on home education and the law, SEN and disabilities, downloadable fact sheets covering many aspects of HE and links to local HE groups across the UK.

## ■ Home Education Advisory Service

Website: <https://www.heas.org.uk/>

Telephone: 01707 371854

Email: [enquiries@heas.org.uk](mailto:enquiries@heas.org.uk)

HEAS is a national home education charity based in the United Kingdom. It is dedicated to the provision of advice and practical support for families who wish to educate their children at home in preference to sending them to school. Interest in home education is increasing and HEAS recognises that reliable information should be available for everyone.

## ■ Home Education and special needs

Website: <http://ehe-sen.org.uk/>

A very comprehensive website about home educating children with special needs.

*“ My son, age 6, (1q21.1 microdeletion) attended nursery in state school, which was a frustrating experience for both of us. He was stressed and exhausted after each school day and developed a stutter. I let him finish the year and then pulled him from school. Home-educating him was the best choice ever. He is able to work at his own pace and with a variety of techniques using a flexible schedule. I put together my own curriculum this year, as well as using sites like ‘Reading Eggs’ [<https://readingeggs.co.uk/>] and ‘Time4Learning’ [<https://www.time4learning.com/>]. Besides his regular curriculum he has the time to learn about topics that interest him, so I feel like he’s further ahead than he would have been in school. We attend park days and field trips every week which keep him socialised and improves his language skills. He likes being home-educated because he gets help whenever he needs it. I’ve received positive feedback about the progress he’s made from his speech therapist and other doctors. He told me last night he also likes home educating because everyone in the family, including dad and his 3-year-old little brother, is involved in his education. ”*

## ■ The World-wide Education Service (WES)

Website: <https://www.weshome.com/>

Telephone: +44 (0)1228 577123

Email: [office@weshome.com](mailto:office@weshome.com)

The World-wide Education Service (WES) provides home education courses worldwide. It is one of the few home-schooling organisations which is accredited by the ODLQC, the national body for quality in open and distance learning. They offer lesson plans and materials in a wide range of school subjects for children aged 4 to 14 years. Their team of specialist tutors monitor their pupils progress and provide guidance for the whole family, supporting and advising parents in the education of their children.

## Home Education links (Non UK)

### ■ Eaton Arrowsmith

Website: <http://www.eatonarrowsmith.com/>

Brain exercises.

### ■ Handwriting worksheets

Website: <https://www.handwritingworksheets.com/flash/cursive/>

Personalised manuscript or handwriting worksheets to print out at home.

### ■ Scientific Learning

Website: <https://www.scilearn.com/products/fast-forward>

Reading and literary resources.



## TRANSITION AND FURTHER EDUCATION

### What is Transition?

Transition is the term used to describe the process of moving from childhood into adult life. Leaving school and moving on can be exciting but also challenging for both children and their parents. There will be lots of changes and choices that need to be made about the future. They may be receiving support from a number of different agencies, including health, social care and education services, and these will all change.

The transition process starts with the Year 9 annual review of your child's EHCP and transition plan which outlines the support provided for your child from age 14 through to age 25 if needed. If your child has an EHCP, he or she will have a transition plan drawn up in Year 9. This helps to plan for their future after leaving school. The transition plan gets reviewed each school year. Your local authority will make sure that your child gets the support they need and will work with social services before your child leaves school.

### Post-16 further education (FE)

The Children and Families Act 2014 proposed a more integrated approach to provision for children and young people with SEND across the 0-25 age range. As part of this change, funding of education and training for young people aged 16-25 in further education (FE college, 6th form college, independent specialist college) changed to bring in a more consistent approach to funding. Young people aged 16-25 moving from statutory schooling into non-statutory further education will be following individual programmes that centre around the young person's own aspirations, interests, strengths, capabilities and needs. It is recognised that support at college will be unique for each young person and needs will not only vary according to individual circumstances but will change over time as they get older and approach adult life. Further education is therefore funded on an individual needs basis to ensure successful individual outcomes. Colleges receive an allocation based on a national funding formula for their core provision. They also have additional funding for students with additional needs, including those with SEN in their main allocation single line budget. Colleges are expected to provide appropriate, high quality SEN support using all available resources. If a college identifies that a young person aged 19-25 with an EHCP or aged 16-19 without an EHCP receiving education at their facility is in need of additional support, they must first explore the local offer and have been through an early help assessment (EHA).

### Get financial help with education costs.

You could get a bursary to help with education-related costs if you are aged 16 to 19 and:

- Studying at a publicly funded school (A publicly funded school is one that doesn't charge you for attending it) or college in England - not a university
- On a training course, including unpaid work experience.



## There's a different scheme in Wales, Scotland and Northern Ireland.

If you're 19 and over you could also get a bursary if you either:

- Are continuing on a course you started aged 16 to 18 (known as being a '19+ continuer')
- Have an Education, Health and Care Plan (EHCP).

More information on **Transition** into adult life can be found in our Transition guide and our guide on Further Education, Training and work, on our website:

<https://www.rarechromo.org/practical-guides-for-families>

## Transition support group

Website: <https://www.facebook.com/groups/transitionchild2adult/>

Transition from child to adult Facebook group was started by Marion who has an adult son with a rare chromosome disorder, to offer support and information to other parents in the UK. This group is a 'private' group for UK parents. Professionals are welcome to join and share useful links etc.



*“ The parent's group on Facebook has helped me feel less alone. It's good to read other's stories, as sometimes we feel very isolated & it's helpful to get things shared, as word of mouth is sometimes best. We know each of us in the group have been through difficult times & we are honest with each other. ”*

*“ We started with little hope and much despair as all milestones were missed. But on the brink of adulthood, B's milestones are measured against the odds , as I see new and astonishing achievements. Never give up hope and never compare unfavourably; for our children are indeed, truly unique. ”*

## Links

■ **ACE Education** Website: <http://www.ace-ed.org.uk/>

Telephone: 0300 0115 142

Email: [enquiries@ace-ed.org.uk](mailto:enquiries@ace-ed.org.uk) (please note no advice via email)

Monday to Wednesday from 10am to 1pm. Term time only.

ACE Education continues the work of The Advisory Centre for Education (it's predecessor). For parents and carers ACE provides independent advice and information on state education in England. For professionals ACE offers a range of high-quality training and consultancy services covering education law and guidance.

■ **CAMHS** (Child and Adolescent Mental Health Services)

Website: <https://www.youngminds.org.uk/young-person/your-guide-to-support/guide-to-camhs/>

Your child may be referred to CAMHS because of ADHD, Anxiety, Autism, Behavioural issues, Depression or other mental health issues. Child and adolescent mental health disorders are surprisingly common. There will be a service in your area. This website helps to explain more about the service and how to get help.

■ **Challenging Behaviour Foundation**

Website: <https://www.challengingbehaviour.org.uk/>

For information and support contact:

Family Support Line: 0300 666 0126 Email: [support@theCBF.org.uk](mailto:support@theCBF.org.uk)

Charity for people with severe learning disabilities who display behaviour described as challenging.

■ **Children's Education Advisory Service (CEAS)**

Website: <https://bit.ly/2H3qqjg>

Telephone: 01980 618 244 (Military: 94 344 8244)

Email: [enquiries@ceas.uk.com](mailto:enquiries@ceas.uk.com)

A tri-service organisation funded by the MOD. It was established to provide information and support to Service families and eligible MOD civilians on all aspects of the education of their children in the UK and overseas.

■ **SEND direct** is a project of the charity **Contact**

Website: <https://www.sendirect.org.uk/>

Education freephone helpline 0808 808 3555

They inform parents about the special education system in the UK and deal with any query they have on transport to and from school, exclusions and home education. Parent guides are free to download. The following guides might be helpful to parents looking for information:

- ⇒ England: a series of special educational needs factsheets
- ⇒ Wales: special educational needs
- ⇒ Scotland: additional support for learning
- ⇒ Northern Ireland: preparing for adult life and transition

## ■ Council for Disabled Children

Website: <https://councilfordisabledchildren.org.uk/>

The strategic partner for SEN and disability to the Department of Education. Children's rights Handbook available, free online here: <https://councilfordisabledchildren.org.uk/help-resources/resources/disabled-children-legal-handbook-2nd-edition>

## ■ Educational Psychologists

Website: <http://www.psychologydirect.co.uk/educational-psychologist/>

Educational Psychologists are trained to identify a wide range of specific learning difficulties in children and adults including: Dyslexia, Dyspraxia and Autistic Spectrum Disorders.

## ■ EHC Plans Support group

Website: <https://www.facebook.com/groups/514182968721112/>

The EHC Plan Support group on Facebook is for Families and Professionals to support each other with Education and Health Care plans.

## ■ Education, Health & Care Plans (EHC plans)

Website: <https://www.facebook.com/groups/1526640527578060/>

A Facebook group run by parents.

## ■ I Can Early Language Programme Website: <https://ican.org.uk/>

General Enquiries telephone: 020 7843 2510

Email: [info@ican.org.uk](mailto:info@ican.org.uk)

I CAN Help is a range of information services that provide help and advice to parents and practitioners about speech, language and communication. It includes a free call-back service with a speech and language therapist.

## ■ KIDS Website: <https://www.kids.org.uk/>

Family support services for disabled children and young people aged 0-25 years, along with their families. Their purpose is to enable children and young people with special education needs and disabilities to enjoy their lives and achieve their ambitions, whilst providing support and guidance to their families.

## ■ Nasen Website: <http://www.nasen.org.uk/>

Telephone: 01827 311500 Email: [welcome@nasen.org.uk](mailto:welcome@nasen.org.uk)

Nasen is an organisation in the UK which aims to promote the education, training, advancement and development of all those with special and additional support needs.

## ■ National Deaf Children's Society (NDCS) Website:

<https://www.ndcs.org.uk/information-and-support/education-and-learning>

Helpline: 0808 800 8880 (freephone) Email: [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk)

The National Deaf Children's Society is the leading charity dedicated to helping deaf children and young people.

## ■ Oxfordshire Family Support Network

Website: <https://www.oxfsn.org.uk/>

Oxfordshire Family Support Network provides independent information, and support by families for families of people with learning disabilities. Set up by family carers who wanted to use their experience to help others in the same situation.

## ■ Parents of teenagers and adult children with additional needs

Website: <https://www.facebook.com/groups/244661355613910/>

A 'private' Facebook group set up by Marion who has an adult son with a chromosome disorder for parents of teenage/adult children with **any** additional needs from anywhere in the world.

## ■ Preparing for Adulthood

Website: <https://www.preparingforadulthood.org.uk/>

Telephone: 01225 789135 Email: [info@preparingforadulthood.org.uk](mailto:info@preparingforadulthood.org.uk)

The Preparing for Adulthood programme is delivered by the National Development Team for inclusion (NDTi) and funded by the Department for Education as part of the delivery for the SEN and disability reforms.

## ■ SEN Action Website: <http://www.senaction.co.uk/>

<https://www.facebook.com/groups/489352661228653/>

Forum for special educational needs, EHC plans and Tribunals

Run by Sean Bowers, a Specialist Advocate and Managing Director of the advocacy firm SEN Action. The group is for parents with children who have special educational needs (SEN) and for young people with SEN. Its aim is to provide a platform for discussion on issues relating to special educational needs, appeals against the Local Authority and the Tribunal process.

## ■ SEN Children Out Of School (Excluded or School Not Provided By LA)

Website: <https://www.facebook.com/groups/979009128837592/>

This group has been set up to support parent/cares whose SEN children or young adults are out of school, due to behavioural needs, medical needs, or because of no suitable schools in their borough, LAs have not provided a school or your child young adult has been excluded permanently or temporarily from their current placement. (Closed group). Join via the link above.

## ■ Special Needs Jungle

Website: <https://www.specialneedsjungle.com/>

Special Needs Jungle creates easy to understand resources, articles and information for parents and carers of children with special needs, disabilities and health conditions to better enable them to navigate the special needs system.

## Education law specialist solicitors and legal advocacy.

### ■ Coram

Website: <https://www.coram.org.uk/how-we-do-it/coram-childrens-legal-centre-upholding-childrens-rights>

Free legal information, advice and representation to children, young people, their families, carers and professionals, as well as international consultancy on child law and children's rights.

### ■ Education Lawyers

Website: <https://www.educationlawyers.co.uk/>

The team provides legal advice and practical solutions in relation to Education issues and in particular, Special Educational Needs (SEN) cases.

### ■ Geldards' education team are experts in special educational needs (SEN)

Website: <https://www.geldards.com/expertise/law-for-families-individuals/special-educational-needs/>

Telephone: 0844 736 0006

Email: [education.enquiries@geldards.com](mailto:education.enquiries@geldards.com)

Facebook: <https://www.facebook.com/GeldardsSEN>



### ■ Irwin Mitchell

Website: <https://www.irwinmitchell.com/personal/protecting-your-rights/education-law>

Telephone: 0808 303 8222 open 24/7, 365 days a year

### ■ Simpson Millar

Website: <https://www.simpsonmillar.co.uk/education-law-solicitors/>  
08082 503 700 (to request a call back) Monday to Friday 8:30am-7:00pm

They offer a range of legal services across England & Wales, advice on School Admissions/Exclusions, tribunals for Children with Special Educational Needs

### ■ Stephensons

Website: [https://www.stephensons.co.uk/site/individuals/education/education\\_law/0333\\_009\\_3922](https://www.stephensons.co.uk/site/individuals/education/education_law/0333_009_3922)

Education law solicitors.

### ■ SOS! SEN on facebook

Website: <https://www.facebook.com/SOSSpecialEducationalNeeds>

Helpline: 020 8538 3731 (term time only)

Free, independent and confidential support for parents and carers of children with SEN.

## More parent quotes

Unique parents have very differing experiences with regard to Education. When we were preparing this guide for the first time, a few *Unique* parents wanted to offer quotes to help other families. Some of the quotes are included throughout this guide, but here are a few more.....

*“ Go with your instincts and don't give up the fight! ”*

*“ Moving my son to a special needs school was one of the best things we have ever done. ”*

*“ One step at a time is our motto. ”*

*“ It's the hardest thing we've faced so far but no matter how hard the fight gets, you've got to keep going until you get what your child needs - you are their voice. ”*

*“ No matter what professional opinions you face; as a parent you know your child's needs best of all. ”*

*“ I feel less isolated and it's great to know my feelings of going insane at times, is normal. It saves moaning and asking people who don't have a clue, for support. ”*

*“ Remember always – you know your child better than anyone. ”*

*“ I found for L [16p11.2 duplication] the process of doing his EHCP was informative and it was lovely to give the team doing his plan a better picture of who L is, by describing his personality, his strengths and his aspirations in his plan. I actually use his plan to show other families how a good EHCP should look and the local authority use it too, as it's full of health and education needs, but also gives you a great look into who L is as a person and that he does have great aspirations in life. ”*

Notes



# Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group  
The Stables, Station Road West, Oxted, Surrey RH8 9EE,  
United Kingdom  
Tel: +44(0)1883 723356  
info@rarechromo.org | [www.rarechromo.org](http://www.rarechromo.org)

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at [www.rarechromo.org](http://www.rarechromo.org)

Please help us to help you!

Our thanks to all of the parents that contributed towards this guide. Thanks also to IASS West Sussex for allowing us to reproduce some of their information on EHCPs.

This guide was compiled by Unique and originally reviewed by David Reid, Headteacher of the Ofsted outstanding special needs school, Manor Green Primary, Lady Margaret Road, Ifield, Crawley, West Sussex. RH11 0DU.

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