

The School Years: Rights, Legislation and Useful Contacts

This document has been put together by CLAPA, with assistance from specialist Health Professionals, parents and teachers. It outlines some of your child's rights in school, lessons that may highlight speech or visual differences and some tips from other parents based on their experience. If you would like more information about your rights in School please refer to the Useful Contacts on page 8.

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Rights/ Legislation/ Education duties

Every child born with a cleft will feel very differently about having this condition. Some children may find certain aspects of school difficult, some won't - It's worth bearing this in mind when reading this document. This page covers certain terms you may hear in school, what these terms mean and your rights with regard to them. This is just a very brief look at rights and legislation so if you need more in depth advice please refer to the specialist organisations listed on pages 7 and 8.

“The school would like your child to go for a SEN assessment” (Teacher/Special Educational Needs Coordinator - SENCO)

What is SEN? (See parents centre and DFES for more information - 'Useful Contacts' document.)
Special Educational Needs (SEN) is a term set out by the Government. It simply means that a child has a learning difficulty or disability which makes it harder for them to learn or access education than other children of the same age. This definition includes difficulties with speech and language or hearing which can be reasons for an assessment being recommended. There are several other reasons a school might recommend a SEN assessment so ask your child's teacher/SENCO if you have any questions.

What is a SEN assessment?

The Local Education Authority (LEA) undertakes the assessment. The assessment can lead to a statement of SEN. This statement is a legal document and sets out what the child's special educational need is and what support the child will require in school. It also names the school which will provide this support. You have a right to choose which school this will be. You can appeal if you don't agree with the statement or if the LEA decide your child doesn't need a statement. Statements can be a good thing for children as it legally sets out what support they are entitled to. The statement will be reviewed each year. If your child doesn't appear to be getting the support set out in the statement you should talk to the school. You can also contact IPSEA (see page 7) for advice.

Scottish parents please note: Additional Support for Learning Act 2004 (Scotland), replaced the law relating to special educational needs on 14 November 2005. For more information about what this means contact [Enquire](#) or [It's Scotland](#) (see pages 7 and 8 for details).

What can I do if my child is being bullied?

“Mum, other kids are picking on me and calling me names because of my lip scar” (Child)
Bullying can be verbal or physical, and can include damage to property and can even take place via text message, on social networking sites and in chat rooms on the computer.

In 1999 an anti-bullying policy was enforced in schools across Britain. Every school should have a policy stating what measures they have in place to prevent bullying and what measures they will take if bullying is taking place. You should encourage your child to talk to their teacher in the first instance. Always reassure your child that they have done the right thing by telling you. If it continues you can make an appointment to go into school and speak to the teacher/Head about it.

- Stay calm at this meeting and take in a copy of what was said in the bullying incident(s), who was involved, where, when and how often.
- Write down your questions in advance.
- Ask for a copy of the anti bullying policy to understand what action the school is likely to take.

There are many organisations such as the charity Kidscape who can offer parents and children further support so you should never feel alone. See 'Useful Contacts' on pages 7 and 8 for more details. The psychologist on your cleft team can also be a huge source of support.

What else can you expect from your child's school?

- You must be given 24 hours notice in writing if a school wants to give your child a detention out of school.
- Legally, you and your child have a right to a copy of your child's school record within 15 school days of you writing to ask for it (Please note – some information may be restricted.) You have the right to vote for parent governors to represent you on the school governing body, you can also stand for election yourself.
- Schools must do all that is reasonable to protect children from bullying.
- If you are not happy about your child's school or education and you want to make a formal complaint, you should get a copy of the schools complaint procedure (all maintained schools must have one).

A School's Responsibilities

Under the **Special Educational Needs Code of Practice** (England and Wales) and the Education (Additional Support for Learning) (Scotland) Act 2004 the school has a duty to meet every child's needs.

Children born with a cleft may require additional support for speech and language, hearing and/or emotional and behavioural support at some time during their education. Just because a child has a cleft lip/palate does not mean that they will automatically need extra support throughout their school life. At times, however, having a little extra support can be really helpful.

Support in England and Wales

If the extra support provided for your child comes from within the school this is described as 'School Action'. **School Action** can include further assessment, additional or different teaching methods or materials, and sometimes additional on-to-one support.

If your child is receiving support and advice from Speech and Language or Hearing Specialists (external agencies), the school should draw up a **School Action Plus, Individual Education Plan** to ensure the specialists' advice is carried out. This could be advice from a speech and language therapist, from the Hearing Advisory Service or a medical diagnosis and report giving recommendations as to how to work differently with the child in class. The action may include advice, arranging further specialist assessment, organising regular visits by a specialist, providing or advising on specialist equipment or a specialist teacher.

For children on both '**School Action**' and '**School Action Plus**' the school should draw up an **Individual Education Plan** (IEP) to record the different or additional provision to be made for the child: teaching strategies, short-term targets for the pupil, success criteria, and what they have achieved.

Practice varies from school to school but both parent and child can be involved in drawing up an IEP.

- Class teachers write the 'School Action' IEP and will be responsible for its delivery. Parents should be invited to an 'educational review' at which they can comment on and accept/discuss their child's IEP.
- Parents should be given a copy of their child's IEP.
- A 'School Action Plus' IEP may be written by the SENCO and will include the advice/action suggested by the external agencies.
- The class teacher is still responsible for seeing that the IEP is carried out.

Support in Scotland

Support in Scotland is tailored to your child's individual needs and where possible support will be integrated into their everyday life at or school. The name of the plan drawn up for your child may vary from school to school, but all children with additional needs should have the following:

- **Personal Learning Plan** – the PLP 'sets out aims and goals for your child to achieve that relate to their own circumstances. They must be manageable and realistic and reflect your child's strengths as well as their development needs.
- The school should arrange for your child to regularly discuss their progress with a member of staff.' (see www.enquire.org.uk).
- An **Individualised Education Plan** may also be considered necessary. This is a specific document that describes in detail the nature of your child's additional support needs and the type of support they require. This may include some support from other agencies.
- If your child needs a higher level of support and has more complex needs, a **Coordinated Support Plan (CSP)** may be drawn up. This is a legal document which brings together the work of different professionals supporting your child.

Parent Partnership Services

All LEAs in England and Wales have a duty to provide 'Parent Partnership Services'. These services provide independent support to parents, can advise parents on their legal rights and put them in contact with other organisations and support groups.

See www.parentpartnership.org for your local branch or phone 0207 843 6058

Or go to the 'directgov' website for more advice and links:

www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds

For more information in Scotland go to: www.enquire.org.uk Help line: 0845 123 2303

Or www.ltscotland.org.uk --additional support for learning – guides

Lessons to Look Out For

The following lessons may highlight issues relating to visual or speech differences so it is useful to be aware of them.

Art and Design

Years 1&2, Unit 1a: **Self portraits**

Years 3 &4, Unit 3a: **Portraying relationships**

Year 7, Unit 7a: **Self Image**

Year 9, Unit 9a: **Life Events**

Science

Year 1, Unit 1a: **Ourselves**

Children may be asked to find and identify parts of the body.

Children may learn about the Senses and discuss hearing.

Growing and changing

Children may be asked to bring in photos of themselves, describe changes since birth, and predict how they will change in the future.

Year 1, Unit 1f: Sound and Hearing

Teachers are guided to provide support for children with hearing difficulties. Make sure you have made your child's teacher aware of any hearing difficulties your child is having.

Year 2, Unit 2c: Variation

Children may be asked to bring in photos of themselves and comment on features that they can/cannot change e.g. hair length, eye colour, facial shape.

Year 3, Unit 3a: Teeth and Eating

Children may be asked to count how many milk teeth they have left using a mirror.

Year 5, Unit 5f: Changing Sounds

Teachers are guided to provide support for children with hearing difficulties. Make sure your child's teacher is aware of any problems your child may be having.

Literacy:

Reception – Year 6: Reading out loud

The focus in lessons is on 'shared' and guided reading in which children are required to read out loud as part of a group.

All Years: Speaking in public

Your child may be asked to speak at assemblies, drama productions, or reading aloud set texts in class. Be ready for uncomplimentary references to 'hare lips' etc (Harry Potter book 2.)

History/Geography KS2, 3 and 4

Be aware of differing attitudes both historically and culturally relating to Cleft Lip and Palate should the subject arise.

Languages

Year 3 onwards: Pronunciation/accents – all languages. Mandarin is a tonal language and can be particularly challenging.

KS2, unit 1: **All about me**

KS2, unit 4: **Portraits**

Music

Children born with a cleft lip and/or palate may sometimes have trouble playing wind instruments. Talk to the teacher to make them aware of this possibility.

A lot of positive work is going on in schools to help our children be confident with who they are and in their relationships with other people. For example, KS1 and KS2 Citizenship units include: developing communication skills; living in a diverse world; building self esteem; bullying; listening to the opinions of others; taking turns; being actively involved.

The SEAL Programme (Social & Emotional Aspects of Learning)

The SEAL programme has been rolled out across schools in England and Wales and addresses the five social and emotional aspects of learning:

1. Self awareness
2. Managing feelings
3. Motivation
4. Empathy
5. Social skills

SEAL covers Key Stages 1 and 2 and includes repeated themes such as: Say No to Bullying (theme 3), Good to be me (theme 5) and Relationships (theme 6.)

This list is not exhaustive. For a more detailed look at the areas your child may be studying each year, go to: www.standards.dfes.gov.uk and choose 'schemes of work' from the drop down menu on the left. Better still, talk to your child's teacher at the beginning of the year as lessons can be adapted and your child's teacher will know exactly what will be covered.

Advice from other parents

The following section contains some hints and tips from other parents based on their own experiences of the school years.

Be proactive! Don't wait to see if a problem arises, prepare your child's teacher in advance, keep them informed of your child's situation to help them to prevent any problems before they arise. Provide some basic information about your child and present it to your child's class teacher, before the first day of term (see 'About Me' document). Don't wait for the school to approach you, they have to deal with thirty children - you have one!

Don't assume that the class teacher knows what a cleft lip and palate is:

'As a teacher myself, I feel that parents need to be pro active with the school and not presume the school understand about clefts. I feel having a cleft is a very complex thing to understand especially as it affects each child in different ways.'

Post information over the summer holidays so teachers see it before school begins

The first day can be crucial. Why not prepare a written summary of cleft, surgery, appointments, areas of difficulty etc.

Don't assume information will automatically be passed to the next teacher

Provide each new teacher with the important information about your child. You can refer them to the CLAPA website www.clapa.com or provide them with our free information leaflet "Children Born with Cleft Lip and Palate: The School Years." (See the website for more details or contact CLAPA on 0207 833 4883.)

Ask for an appointment with the SENCO to make sure s/he understands what having a cleft means and what is involved. Find out the following:

- How s/he will inform the rest of the school and make sure that cover staff, kitchen staff etc are aware? Lunch break can sometimes be a difficult time if your child is being bullied when mixing with older / younger children who do not know them.
- Will your child have a support plan or an IEP?
- How will the school work with external agencies? E.g. providing a room/quiet space for the Hearing Impaired Advisor to work with your child.

Talk to the child's teacher about lessons that might be challenging for your child

Ask how they are going to approach potentially sensitive subjects. Give them a copy of CLAPA's 'Lessons to Look Out for' (pages 3 and 4). Ask for your child to be paired with a child who would be sensitive to their needs when the class study sensitive subjects, such as teeth.

If something is worrying you talk to the teacher or write to the school

"I wrote to the school to say [my child] had not had a speaking part [in three years] – this autumn he got his first speaking part."

Prepare your child

Young children are very honest and may well comment on your child's appearance, speech, hearing aids etc. The majority of times this is not meant to be rude or cruel and is just youthful curiosity. Help your child deal with this by talking about situations that might come up and practising replies before they start school.

“My daughter has developed almost a ‘mantra’ that she repeats to any curious children who ask about her cleft. She says ‘I was born with a hole in my lip, the doctors sewed it up and this is the scar.’ Plain and simple. No exaggerations and very matter of fact. It has worked up to now.”

Help your child to practise distracting other children from asking too many questions by changing the subject. E.g. “I was born with a hole in my lip, the doctors sewed it up and this is the scar. Have you seen the latestfilm / fancy a game of football? Cool shoes, where are they from?”

If bullying/teasing occurs:

- Listen to and support your child.
- Go to the Kidscape or Changing Faces websites for excellent advice on how to deal with bullying. The Cleft Team psychologist can also offer support.
- Find out if your child has spoken to their teacher any if steps have been taken to resolve the problem.
- Why not make a ‘five finger friend list’ with your child: The child draws around their hand and names each digit with a trustworthy adult who they know they can go to if they need help. That way the child always knows who to turn to if they need to.
- Contact your child’s teacher to request action or confirm that things are being resolved.
- If there are further problems ask to see the SENCO or Head teacher and ask for action to be taken quickly. Don’t allow things to build up.
- Read the school’s anti-bullying policy: Has the school acted in line with the policy?

Don’t make a cleft the focus of your child’s education

Bolster your child’s self esteem by focussing on their achievements and what they are enjoying in school.

Keep the school informed:

Let them know in advance about appointments and time off school for operations. Ask how your child can have access to work missed and catch up.

“When my child had his lip revision, the whole class made cards and sent them to him – he was delighted!”

Keep good records – you get asked all sorts of things!

Different professionals may require information from you at different times. For example the dates of previous operations, the names of staff, how many grommet operations your child has had etc. As the years go by it gets harder to remember and is much easier to keep a written record, with all the information in one file.

Useful Contacts

- Children’s Legal Centre (www.childrenslegalcentre.org.uk)
- National Education Line via Community Legal Advice: 0845 345 4345
Lines open Monday – Wednesday 9:00 – 17:00, Thursday – Friday 9:00 – 18:30
- Scottish Child Law Centre (www.sclc.org.uk)
0131 667 6333
- Community Legal Advice (www.clsdirect.org.uk)
Free, confidential legal advice: 0845 345 4 345
- Child Law Advice Line 0845 1202948

- Young People Freephone: 0800 783 2178
- Department for education and skills (www.dfes.gov.uk)
Information about educational policies and much more
- Independent Panel for Special Education Advice (IPSEA) (England & Wales) (www.ipsea.org.uk)
Advice about statements and going to appeal and tribunal
Freephone; 0800 0184016
- Enquire – www.enquire.org.uk
08451232303 (Scottish Advice service for additional support for learning)
- The Advisory Centre for Education (www.ace-ed.org.uk)
Offers general advice about state funded education and specialist advice on exclusion.
0808 800 5793 (general advice)
- AFASIC (www.afasic.org.uk)
Information about unlocking speech and language
Helpline - 0845 3 55 55 77
- Changing Faces (www.changingfaces.org.uk)
Has a specialist schools support service for parents and children and they also facilitate workshops including transition from primary to secondary school.
Call 0845 4500 275 for more information, support and advice
- Cleft Lip & Palate Association (www.clapa.com, www.clapakidz.com, www.clapaedge.com)
Offers support and advice to children with clefts and their parents plus a whole range of services including summer camp and workshops.
0207 833 4883
- Contact a Family (www.cafamily.org.uk)
Information about support groups for rare disorders and specific conditions. Provides useful publications including bullying.
Freephone 0808 808 3555
- Childline – www.childline.org.uk
0800 1111
- Kidscape – www.kidscape.org.uk
Advice and information about bullying
08451 205204
- Respect me – www.respectme.org.uk
Scotland's Anti-bullying service
AND
www.youngscot.org – Information for 11-26 year olds in Scotland
- It's Scotland - www.itscotland.org.uk/parentzone
Information for Scottish parents
- Parents Centre – www.parentscentre.gov.uk (England and Wales)
'Helping you to help your child'
- Parentline plus – www.parentlineplus.org.uk
A national charity that supports and works with parents
0808 800 2222