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For the UK
cleft community

Teachers' Guide

Supporting Young
People Born with a
Cleft at Primary School



About This Guide

This guide is intended to help teachers understand some of the issues a child born with a cleft might face at school and what you can do to help.

It is aimed at Primary School teachers and staff, but nursery and secondary school staff may also find it useful.

Everyone born with a cleft will feel differently about it. It's important to avoid making assumptions about how someone might feel about their cleft based on how 'noticeable' it is to you.

Many children will not want to draw extra attention to themselves or their cleft, so any interventions involving the rest of the class should be carefully discussed with the child and their parents or carers first.

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About Cleft Lip and Palate

In early pregnancy, different parts of a baby's face develop separately and join together. If they don't join fully, the baby is born with a gap or 'cleft.'

This gap can be on one or both sides of their top lip (**cleft lip**), in the roof of their mouth (**cleft palate**), or both (**cleft lip and palate**). The causes are complicated. It's usually a mix of lots of different genetic and environmental factors.

One in 700 babies are born with a cleft. That's around **1,200 every year** in the UK.



How does a cleft affect education?

While many children born with a cleft excel at school, overall, their educational attainment is slightly lower than their peers. Research hasn't found any medical reason for this, which suggests that it's because of other reasons, like a lack of support. This guide explains the barriers that children born with a cleft can face in education and how teachers and other staff can help them to meet their full potential.

Is cleft a disability?

A cleft by itself is not generally considered a disability. However, each case is unique. A cleft could affect someone's speech, hearing, eating or self-esteem in a way which is significant and long-term enough that this would be considered a disability. When schools are looking at what support and accommodations should be made available, it's usually more helpful to look at the issues and barriers an individual child faces rather than the specifics of their condition.

A '**visible difference**' is a condition, mark or scar which alters someone's appearance. The legal term for this is 'disfigurement', which gives affected people extra protections under the 2010 Equality Act.



How is a cleft treated?

NHS Cleft Services provide comprehensive treatment into adulthood. This can include:

- One or more **surgeries** to close the cleft between 3-12 months old
- Additional surgeries to help with **speech, dental concerns, breathing, and appearance**
- **Speech therapy**
- Help with **hearing**, which could include hearing aids or grommets
- Extensive **orthodontic** work
- **Psychological** support

Some children will have had a single surgery before their first birthday and need no further medical interventions other than monitoring from their Cleft Team.

Others will arrive at school having had multiple surgeries and other treatment which may be ongoing.

It's important to understand each child's individual circumstances to best support their needs and help them succeed at school.

Time Off School

Children and young people born with a cleft will need time off school for medical appointments and treatments, which may include surgery.

These may take place in local clinics, or in a specialist NHS Cleft Team which could involve a lot of planning and travel to attend.

Unlike routine dental or other appointments, these are not easily rearranged for a time which better suits the school. Families may be given a surgery date at the last minute, and this may be cancelled or rearranged without warning.

If they need regular treatment, such as Speech and Language Therapy, they may need to come out of class more frequently.

It is often not possible for these appointments to be scheduled outside of school hours, meaning that children can miss out on attendance awards or even receive warning letters about 'persistent absences'. This can happen even when absences have been arranged and authorised in advance.

How can schools help?

Upcoming appointments, especially surgeries, can be a source of stress for young people. It helps if the school is supportive and does not make them or their families feel at fault for needing to miss school.



Review and adapt your attendance reward policy so it doesn't exclude pupils absent for medical reasons.

Work with parents to ensure children are given a chance to catch up on any work they've missed and aren't blamed for their absence. **5**

Speech

Half of all children born with a cleft palate (a gap in the roof of the mouth) will have ongoing speech therapy. By the time they start school, around 40% of these children will still have speech which is 'noticeably different' to their peers. They may sound nasal, struggle to make certain sounds, or otherwise be hard to understand.

This might make a child self-conscious about their voice, and they may avoid talking or get easily frustrated by the need to repeat themselves. This could affect how they join in with the class and interact with their peers.

Certain lessons or activities may be extra difficult. This could include [music lessons](#) (children born with a cleft palate may struggle to play wind or brass instruments), [languages](#) (they may not be able to physically make certain sounds), and [reading out loud or speaking in front of the class](#). They might also have difficulties in using a straw or blowing a balloon.

How can schools help?

Lessons or activities involving speaking or blowing must be approached sensitively, with [exceptions or alternatives](#) offered where possible.

[Avoid interrupting or 'correcting' their speech](#), as this can cause anxiety around talking. If you have to ask the child to repeat themselves, do this discreetly, try to do this only once, and repeat back clearly what you think the child is trying to communicate to make sure you understand them.

Be patient, encourage children to use their voices, and praise their successes and milestones. If possible, teachers should work with parents/carers and a child's Speech and Language Therapist to support their therapy targets.



Hearing

'Glue ear' is a common childhood condition which can cause hearing to be 'muffled', almost like someone is underwater. Children born with a cleft palate are more likely to develop glue ear, which is more likely to be recurring.

Because glue ear can develop gradually, children may not realise anything is wrong. You may notice that a student:

- Doesn't respond when their name is called
- Appears to ignore or misunderstand instructions
- Watches what others do before doing it themselves
- Watches people's faces and lips while they're talking
- Talks too loudly or softly
- Gets easily tired and frustrated
- Becomes more physical in their attempts to communicate

How can schools help?

Look out for these signs and alert parents or carers if you suspect a child's hearing might be affected.

It can help to sit the child somewhere in the room where they can clearly see the teacher's face. Using pictures and other visual aids can help a child follow along with the discussion.

It may be especially challenging for children to maintain concentration during group work if they have to lip-read and actively listen. Encourage pupils to signal when they will talk in a group and to take turns. It can also help to reduce background noise.

Special allowances may also need to be made for examinations that involve listening to tape recorders in large rooms or learning in environments where there may be a lot of background noise.

The National Deaf Children's Society has more tips for supporting children in the classroom at www.NDCS.org.uk

Appearance Concerns

Children with a cleft lip may have a visible scar. They may have missing or crooked teeth and will often wear braces or start other orthodontic treatments before their peers.

From around 6-7 years old, children may start to feel self-conscious about their appearance, and this can have a negative impact on their confidence levels and class participation.

They may also experience bullying or uncomfortable comments about their appearance from other young people.

How can schools help?

If a child is particularly conscious about their appearance, take extra care to look out for teasing or comments around this and support children who wish to explain to the rest of the class why they may look different.

Be aware of lessons or topics that may bring up issues concerning a child's cleft or appearance (e.g. self-portraits), and make sure to approach these sensitively.



Low Self-Esteem

Children who look and/or sound different may have low expectations of themselves and believe others do too. This can affect how they participate or behave in class and at break times, as well as how they perform academically. They may behave in ways that can be seen as disruptive, such as refusing to do tasks or becoming aggressive, or they may become more insular.

A cleft is just one of many reasons why a child might be showing different behaviour or struggling with their self-esteem, so it's important to also consider what else may be going on in their lives.

How can schools help?

Being aware of these issues is the first step toward managing them.

Several strategies might help. For example, teachers could ensure that groups for activities are chosen by some other means than popularity or friendship groups.

Recognising a child's abilities and encouraging them to focus on and develop these can be a big help. Children often become aware of these abilities for the first time by having them named and being able to talk about them, even if these abilities are simple things like being compassionate or enthusiastic.



Questions from Others

Children born with a cleft may get questions and comments from classmates about their cleft. Even when these are well-meaning, they may be upsetting for children who don't know how to answer or who are particularly sensitive to others noticing their difference.

How Schools Can Help

Have a basic understanding of cleft lip and palate. Treat it like any other trait a child might be born with, such as eye colour, to avoid them feeling embarrassed. You could mention their bravery in dealing with surgery and hospital appointments.

If you think it would help, encourage children to come up with a simple way to explain their difference to others who ask, e.g., 'I was born with a hole in my lip, but doctors sewed it up when I was a baby.'

Talking About Cleft in Class

Having a child born with a cleft in the class is a good chance to talk to pupils about diversity, acceptance, and empathy.

If you are interested in doing a lesson about cleft, and have a child in your class who is comfortable talking about cleft and their journey, then it is a good idea to invite them to talk to their class about their cleft and what this means for them.

If the child isn't comfortable with talking about it themselves, they may be happy to have you talk about it instead. You can use the discussion points on the next page to help cover how we are all different in our own way.

Discussion Points



Everyone is made differently. Ask pupils to name one thing that is different or unique about them.



Ask the class to think about what the world would be like if we were all the same and then about the benefits of us all being different.



Ask pupils to think about someone else in the class – what differences and similarities do they have with one another, and how does this change their relationship?



Ask the class to consider why people might have medical treatment or surgery (e.g., injuries, health reasons, appearance, etc.). How would they feel if they needed an operation? What would they bring with them to the hospital? Who would they like to visit them?



Ask the class to describe the person next to them in three words that have nothing to do with their appearance (e.g., funny, kind, loves dancing).



Ask the class to think about the most important qualities of a friend. Pick out when they focus on things that concern someone's personality, not how they look or sound.

