

## Language and Terminology Guide

This guide is intended to explain what CLAPA as a charity believes are acceptable and appropriate ways to talk about people with and affected by cleft lip and/or palate, as well as the condition itself.

The results of our 2014 Spring Survey of our members in which we asked about opinions on certain words and phrases were taken into account when creating this document.

### **People First Language**

In general, we would like to encourage everyone in the CLAPA Community to use what is called '[People First Language](#)' when talking about anyone with a cleft.

A person with a condition is *not* that condition – there are many other things that should and do define that person. Even if you have the best of intentions in using these terms, this may not always come across, and we feel strongly that it is up to the individual with the condition to decide what terms they prefer to be used, not just their parents or carers.

**Instead of** “I have a cleft child/baby” **use** “I have a child/baby with a cleft” or “My child/baby has a cleft”

**Instead of** “Cleft mum” **use** “Mum of a child with a cleft”

**When in doubt** – the best name to call someone is the name they were born with. Use names where possible, and when discussing people born with a cleft, always put the person first.

### **(Born) With**

When talking about adults, teenagers or young people, CLAPA will usually say '**born with a cleft**' as oppose to '**with a cleft**'.

This is because in most cases their cleft will have been surgically repaired, so even though it may have ongoing effects on them, it is something they were born with rather than something they 'have'.

### **Cleft/Clefts**

We refer to cleft and types of cleft as singular, so 'people born with cleft palate' rather than 'cleft palates' or 'clefts'. When referring to multiple individuals we will still use cleft as singular, e.g. 'Jane and John, both of whom were born with a cleft lip' rather than 'with cleft lips'.

### **Inclusive Language**

CLAPA tries to use language which is as inclusive as possible so that we do not leave anyone out, and only use specifics when we are talking about a specific group.

When referring to the condition itself, we use '**cleft lip and/or palate**' or just '**cleft**' to talk about all types and combinations of cleft of the lip and palate. If we wished to single out one type of cleft, we would say, for example, 'cleft palate' to refer to everyone with a cleft palate (including those who *also* have a cleft lip) or 'isolated cleft palate' to talk about people with cleft palate *only*.

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When referring to the CLAPA Community, we talk about **'people affected by cleft'** as this includes everyone whose lives have been affected by cleft lip and/or palate in some way, including people born with a cleft, their families, friends and even (though not as directly) cleft health professionals. The word 'affected' is intended to be neutral and has neither positive nor negative implications, as people have very different experiences of cleft in their lives.

### Outdated or Offensive Terms

**'Hare Lip', 'Hair Lip' or 'Harelip'** – This is an outdated term for a person with a cleft lip and is widely considered to be offensive. It is sometimes misheard as 'hair lip', which is sometimes thought to refer to a thin hair-like scar on someone's lip, but much like 'harelip', the origins of this term make it offensive to many. In all cases, we prefer to use the name of the condition (**'cleft lip'**).

**'Disfigurement' or 'Deformity'** – Some organisations like Changing Faces use these terms, partially for their legally protected meaning. At CLAPA we prefer to use the more neutral term **'visible difference'**, which refers to a visibly altered appearance due to surgery or a condition of some kind.

**'Birth defect'** – This phrase has negative connotations. We prefer to use the phrase **'congenital abnormality'** (meaning a difference that someone has inherited or was born with) as it is more neutral. In general, we will refer to cleft as a 'condition' rather than using either of these other terms as it is both neutral and widely understood.

### Other Medical Terms

**'Repair surgery'** – We use this phrase as it is medically accurate and describes a specific surgical procedure, it is not intended to have any other implications.

### Nicknames

**'Clefty'** – We understand that parents may use this word to refer to their children or that people with a cleft may use it to refer to themselves. After consulting with people in our community with a range of opinions, CLAPA's position is that we will not use this term, and we encourage those who wish to use it to consider our reasons for this decision, which are as follows:

1. Using this as a nickname can reduce a person to a condition they were born with.
2. It can sentimentalise a condition which can be very difficult for some parents and/or people born with it to cope with.
3. Many parents and individuals with a cleft find the word belittling and/or offensive, and are strongly against others using it to refer to people born with a cleft as a group.

While we understand that parents may use this word to refer to their own children, we would ask that they refrain from using this word when referring to other people's children, and that they understand that other people may have a very negative reaction.

If an individual with a cleft wishes to use this word to refer to themselves, they are free to do so as we strongly believe it is up to the individual to decide what words they wish to use about themselves, but we would ask that they only talk about themselves in this way.

If you have any questions or concerns, please contact [anna.martindale@clapa.com](mailto:anna.martindale@clapa.com)