Language and Style Guide

USING THIS GUIDE

This guide is intended to help staff (and volunteers working on our behalf) write and talk about CLAPA and our work in a consistent way which aligns with our values, respects our diverse community, and is inclusive to all.

Cleft is a condition which can in theory affect anyone in the UK. People affected by cleft will have varied experiences and feelings associated with the condition. CLAPA aims to support people of all ages and backgrounds, and wishes to create a community which is inclusive and open to all. It is therefore crucial that the language CLAPA uses is inclusive and does not make assumptions about someone's background, circumstances or feelings about cleft.

This guide, together with our Diversity Strategy, explains our point of view when choosing what words and phrases to use, and provides examples. These examples will not apply to all scenarios, but we ask staff to consider the intent behind them when considering how this applies to their own writing.

Throughout this policy we will list exceptions to the general rules when writing in '**closed environments**'. This refers to writing not for the general public or the cleft community, but in the context of fundraising applications, research papers, or other areas in which we may need to use more forceful and/or clinical language to get a point across.

In all cases, staff are advised to use their best judgement alongside this guide, and to seek a second opinion when in doubt.

ABOUT CLEFT LIP AND PALATE

Staff should familiarise themselves with the [information on CLAPA's website](#) about types of cleft to ensure they use the correct terms.

In general, when communicating about cleft, staff should keep in mind the wide range of ways people are affected and how they may feel about this, and avoid making assumptions or generalisations.

We refer to cleft as a '**condition**', as this is a neutral way to refer to a way in which someone's health is affected without making assumptions about the impact this may have on them. Cleft itself is not an illness, sickness or disease.

A cleft by itself is not a **disability**, though it may affect someone in a way which means they need extra support, e.g. hearing aids, speech therapy. In some cases, the extra support needed is substantial and long-term enough that it may be considered a disability. It can also be helpful to look at cleft under the 'umbrella' of disability when considering what extra support could be made available to families in need.

People First Language

CLAPA uses '[People First Language](#)' when talking about anyone with a cleft. This means we mention the individual before we mention their condition. This is not preferred for every condition or difference, but when communicating about cleft please use the below examples as a guide.

Instead of "cleft child/baby" **use** "child/baby born with a cleft" or "[Name] was born with a cleft"

Instead of "Cleft mum" **use** "Mum of a child born with a cleft"

We use 'born with a cleft' rather than 'has a cleft' as people who are no longer in treatment may not consider a cleft to be something they 'have', just something they were born with.

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

Clefty: Individuals born with a cleft should not be referred to as 'clefty' or 'clefties'. This reduces a person to a condition they were born with, and is often seen as belittling or patronising.

Exception: We believe it is up to the person with a condition to decide what terms they prefer. If someone uses the term 'harelip' to refer to themselves, or says they were a 'clefty' or 'cleft baby', etc., we will not 'correct' them or change this when quoting them. If you're concerned this may cause offence, you may find it helpful to include a note explaining this policy.

Cleft/Clefts

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

Inclusive Language

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**' (or 'cleft palate on its own', etc.) to talk about people with cleft palate but not a cleft lip. Avoid using terms such as '<u>**only**</u> **has a cleft palate**' outside of a medical or other formal context, as this can minimise the impact of a particular kind of cleft on a person.

We use **'people affected by cleft'** as shorthand for everyone whose lives have been personally affected by cleft in some way, including people born with a cleft, their families, close friends, and anyone else who may need support in relation to someone being born with a cleft. 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.

Describing Differences

When describing people born with a cleft, use neutral language which acknowledges a difference without placing a value judgement on this difference, assuming the impact it has on the individual, or implying it's the fault of the individual or their parents.

Instead of "Children born with a cleft have problems with their speech and appearance," **use**, "Children born with a cleft may look or sound different to their peers," or "A cleft can affect speech and appearance."

Instead of "A child born with a cleft may have speech problems," **use** "may find it difficult to make certain sounds", "may speak in a way which other people struggle to understand."

We use the term '**visible difference**' to describe an appearance which is altered as a result of a congenital or acquired condition, accident or surgery, such as a scar from a cleft lip repair surgery.

Unless it's used in a medical/research context, we **don't** use value-laden terms such as **normal/abnormal**. When these must be used, we use inverted commas as a distancing device to indicate we don't entirely agree with its usage and understand it may not be helpful for people who find themselves outside of this 'normal' bracket. The term 'norm' is preferred as this describes an average, and doesn't imply something is or isn't acceptable.

Exception: In closed environments such as funding applications, it may be necessary to put more emphasis on the difficulties faced by people affected by cleft in order to make an effective, emotive case about the need for CLAPA's support. We may use stronger language or use more value-laden terms in an attempt to get this point across.

Outdated, Offensive or Negative 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. In all cases, we prefer to use the name of the condition (**'cleft lip'**).

'Disfigurement' or **'Deformity'** – These have negative connotations for many people. Use '**visible difference**' or '**congenital abnormality**' as appropriate instead. Some organisations (such as Changing Faces) use 'disfigurement' because of its legally protected meaning. This term may be used in this context, but the reason must be made clear.

'Birth defect' – This term has negative connotations and should not be used. In a medical context, the term **'congenital abnormality'** (meaning a difference that someone has inherited or was born with) should be used as it is more neutral. In general, we will refer to cleft as a '**condition**', '**facial difference**' or '**condition a baby is born with**' rather than using either of these terms, as this is both neutral and widely understood. E.G. 'Cleft lip and palate is the most common facial difference a baby can be born with'.

Describing Surgery

The preferred way to describe any kind of surgery is by describing what it intends to do in a neutral way, making sure to include any functional concerns (e.g. breathing, eating) when applicable. Where appropriate, the medical name of the surgery should be included in brackets afterwards to help familiarise readers with the medical terms they may need to use in the future.

For example, 'Surgery to fill the gap in their gum so adult teeth can come through properly (Alveolar Bone Graft)' or 'Surgery to realign the jaws and change the profile (osteotomy or orthognathic surgery)'.

Avoid using terms with a value judgement such as 'improve' or 'fix'.

Instead of 'Surgery to fix the shape of her nose', **use** 'surgery to change the shape of her nose,' or 'surgery to change the shape of her nose and help with breathing (rhinoplasty)'

Instead of 'Surgery to improve the appearance of a scar," **use** "Surgery to make a scar less visible."

We use the general term '**Repair Surgery**' when describing surgery to close a cleft palate and/or cleft lip performed on a baby or very young child. This is useful shorthand, but describing the purpose of the surgery as above is still preferred.

Writing with Respect

When writing about people affected by cleft, and particularly about people born with a cleft, staff should take care not to sensationalise cleft or the ways in which it may affect someone's life, and to always take care to humanise the subjects of any case studies used. While CLAPA as a charity must make a case for its work by highlighting the needs of our stakeholders, there are ways to do this effectively without patronising or infantilising people affected by cleft.

Avoid evoking pity for the subject, and never suggest that the audience's inaction will cause harm to a particular individual (e.g. "Without your help, Tom's local CLAPA group will be shut down and he will be isolated and alone.").

Avoid overly patronising phrases about how someone's personality or another quality is more important than their appearance (e.g. "It's what on the inside that counts"), as this is typically uncalled for and assumptive of an individual's values and views of cleft.

Readers should never be asked to express an opinion on someone's appearance (e.g. "Like this post if you think Jane is beautiful regardless of her cleft!"), and a particular person born with a cleft should never be used to 'prove a point' (e.g. "The media doesn't believe people with scars are beautiful, but look at Jane!").

ABOUT CLAPA

In writing, CLAPA should be introduced as 'the Cleft Lip and Palate Association (CLAPA)', and later on referred to as 'CLAPA'. The word 'and' should be used rather than the ampersand (&), though the ampersand is used in our logo.

'CLAPA' is always capitalised, it should never be written as 'Clapa'.

The Charity's Work

Refer to the Branding Guidelines for specific guidance and examples to help with writing about CLAPA's work, including guidance on tone.

The CLAPA Community

The 'CLAPA Community' is shorthand for people who are active on our e-mailing list, as these are people we are able to directly contact with relevant information and regular updates. We use 'Join the CLAPA Community' to invite people to join our mailing list.

WRITING FOR A DIVERSE AUDIENCE

General

Where possible, write in Plain English. Be precise and direct, cut out surplus words, avoid jargon (and/or explain jargon and acronyms when necessary), and try to stick to simple words and phrases. Keep sentences and paragraphs short, and simplify your structure to aid understanding. Avoid obscure idioms or figurative language such as metaphors.

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Avoid making specific cultural references, like a particular singer or a brand of shoes. Do not make assumptions about things that 'everyone' does, such as driving or working. Keep your references broad and inclusive.

If you have any doubts, ask a colleague to check your work for readability and sensitivity. There are a number of helpful apps such as [Hemmingway](#) and [Grammarly](#) which can also be used to improve writing.

Gender and Family

When talking in general terms, avoid unnecessarily **binary** language such as 'his or hers'. 'They' and 'their' are almost always preferred.

Instead of 'Contact his or her school,' **use** 'contact their school' or 'contact your child's school'.

Never use 'he' or 'she' to refer to a hypothetical individual (e.g. "A child born with a cleft may find as he grows up that…"). Use 'they' and 'their' instead.

Do not use irrelevant modifiers like 'woman doctor' or 'male nurse', and be mindful of stereotypes implied by terms like 'housewife'. Avoid the feminine (i.e. non-standard) forms of nouns such as 'comedienne' or 'hostess', as these can sound belittling. Avoid referring to people in particular in terms of their appearance, marital status, or other terms which may be belittling (e.g. using 'boy' or 'girl' when referring to an adult).

Do not use 'man' or 'mankind' to refer to people in general – use 'person', 'people', 'humankind' or 'humanity' instead. Avoid unnecessary gender-specific terms, e.g. 'manning a stall' or 'layman'.

Do not assume the **structure of a family**, or the home life of a child or young person. Avoid using terms which imply a 'traditional' nuclear family or assume the **gender** of anyone involved.

Instead of 'Mother and father', **use** 'Parent or Carer', or plurals as appropriate (e.g. 'Contact Tom's parent or carer' vs. 'Parents and carers should note…').

Instead of 'Spouse' or 'Husband or Wife', **use** 'Partner' unless there is a legal reason to use another term.

When talking about the people looking after a child, **instead of** 'Parents' or 'Mum and dad', **use** 'Parents and carers', or 'the people involved in a child's care'.

When **writing for a child**, use 'an adult you trust' or 'the person who looks after you'.

Age

Avoid words or phrases which are derogatory or patronising towards older people, such as 'old folks'. The term 'elderly' is regarded by some to be depersonalising and distancing; more neutral terms such as 'older people' should be used where necessary, though staff should consider whether it is necessary for age to be mentioned at all.

There are similar considerations when writing about children and young people. When writing for a young audience, staff should take special care to ensure their work is accessible, and seek help when necessary. While making their writing accessible and relatable, staff should keep in mind their role as

a professional adult and avoid attempts to pander to or mimic youth culture, as these are often unsuccessful and come across as patronising.

Disability

The general guidelines outlined above about writing in a respectful, non-patronising way about cleft will apply here.

In most cases, 'People First Language' (see above) is preferred when talking about people with a disability, but there are many exceptions, and often there is no 'right' answer. If in doubt, staff should seek guidance from prominent support charities to understand more about what terms are broadly preferred by people with a particular condition or accessibility requirement.

When relaying accessibility information (e.g. about ramps, induction loops, etc.), language should focus on the accommodations and/or tools required rather than specific conditions. For example, use 'wheelchair users' instead of 'paraplegics', or 'those with hearing aids' rather than 'the hard of hearing'. This is because the accessibility information is aimed at those accommodations/tools rather than any conditions or even the individual, whose access requirements may fluctuate.

While most people with disabilities are unbothered by common phrases like 'nice to see you', take care not to use words or phrases which equate a condition with a shortcoming, such as 'blind spot' or 'fall on deaf ears'.

Geography, Nationality and Ethnicity

CLAPA is a UK-wide charity working with a range of people from different backgrounds. Staff should be mindful of this when writing and carefully consider their own conscious and unconscious biases related to cultural and geographic differences. Assumptions must not be made about people's national origin, or their religious, cultural or linguistic background.

Avoid being 'Anglo-centric' and assuming that what applies to England (and London in particular) applies equally to the rest of the UK. If parts of the UK are excluded from something by design (e.g. the CRANE database currently does not collect data from Scotland), this should be made clear and the reasons should be explained. The term 'UK-wide', rather than 'nationwide' is preferable when referring to the entire UK.

CLAPA's services are available to all those in the UK regardless of nationality. When talking about people, staff should avoid terms like 'British' and use 'people in the UK' instead.

Avoid mentioning someone's ethnic, religious or cultural background unless it is of particular relevance and they have given their permission to do this. In these cases, staff should use the terms chosen by the individual, or, if they are unsure of this only repeat these terms in a quote.

QUOTES & CASE STUDIES

In all cases when collecting case studies, stories and quotes, authors should be made aware their submissions may be edited for clarity, grammar, spelling and length. In practice, editors should use their best judgement about the intentions of the author and seek clarification when necessary.

Spelling, grammar, and other minor edits should be made if the editor is certain of the author's intentions and is confident that their edits preserve the original meaning. However, care must be

taken not to over-edit or otherwise erase the voice of the original author. Sections of a case study which are not usable should be removed rather than edited into something unrecognisable.