

Every smile
tells a story



Strategic Plan 2018-2021



Contents

- 1: Executive summary 3
- 2: Organisation Details..... 4
- 3: What CLAPA Does 5
 - 3.1: What is the Public Need?..... 5
 - 3.2: Our Vision..... 5
 - 3.3: Our Mission Statement 5
 - 3.4: Our Values..... 5
 - 3.5: Our Activities..... 6
 - 3.4.1 Community..... 6
 - 3.5.2 Support..... 6
 - 3.5.3 Knowledge..... 6
 - 3.5.4 Empowerment 6
- 4: The Next Three Years..... 7
 - 4.1 Objectives & Activities** 7
 - 4.1.1 Governance 7
 - 4.1.2 Finance 8
 - 4.1.3 Staff & Management..... 8
 - 4.1.4 Fundraising..... 9
 - 4.1.5 Communications 9
 - 4.1.6 Volunteering/services 10
 - 4.1.7 Partnership..... 10
 - 4.2: Annual Operational Plans 11
 - 4.2.1. *Looking Back on 2017/18*..... 11
 - 4.2.2: *In 2018/19* 11
 - 4.2.3: *In 2019/20*..... 12
 - 4.2.4: *In 2020/21* 12
- 6: Managing Risks 13
 - 6.1 SWOT Analysis..... 13

1: Executive summary

This document sets out CLAPA's vision and strategy for the period April 2018 – March 2021.

As we approach our 40th anniversary, we are proud to say CLAPA is a well-respected organisation in the cleft world, with a reputation for providing quality, evidenced-based services for young families, and for our close working with researchers and NHS teams.

The independently-evaluated success of our Regional Coordinator Project has demonstrated the need for locally-led, targeted services alongside those delivered from the national office, and as we move into a time of political and financial uncertainty, a key priority for CLAPA will be preserving these services as much as possible. That is why the key concept of our strategy for the next three years is sustainability.

To this end, 2018-2021 will see us working “behind the scenes” to consolidate and develop our existing services with the greatest impact to ensure they can continue to support people affected by cleft for many years to come. Our reliance on grant funding is a great threat to our sustainability, as such funding becomes more and more difficult to secure, so it is imperative at this time to develop our fundraising practices to ensure we have a diverse set of broad, stable income streams to support our work moving forwards. Ongoing development of our communications channels and practices will support this, with the departments working closely together to embed fundraising throughout our work.

The delivery of the Adult Services Project (from March 2018) coincides with this strategic period, and we will do everything we can to support the work of the new Adult Services Coordinator in researching and supporting this historically under-served group. However, we will not seek to develop new services unless they are time-bound, fully funded, within our capacity, and serve a wider goal of growing the CLAPA Community.

Finally, in reference to our wider theme of sustainability, this period will see a strong focus on staff wellbeing and on developing CLAPA from the inside-out to ensure the core of the organisation remains strong as we work to overcome the unique challenges the next three years will bring.

2: Organisation Details

2.1: Charity Name:

The Cleft Lip and Palate Association (CLAPA)

2.2: Address:

Green Man Tower
332b Goswell Road
LONDON
EC1V 7LQ

2.3: Telephone number:

Tel: (020) 7833 4883

2.4: E-Mail:

info@clapa.com

2.5: Website:

www.clapa.com

2.6: Legal status:

Charity Commission of England & Wales Registration No. 1108160
Company Registration No. 05206298 (England and Wales)
Office of the Scottish Charity Regulatory (OSCR) Registration No. SC041034

2.7: Objects

1. The relief of and support of all those with cleft lip, cleft palate or both or associated cranio-facial birth anomalies;
2. The promotion of research into the causes of and the relief treatment or care of those with cleft lip, cleft palate or associated cranio-facial birth anomalies and conditions or any of them and to publish the useful results of such research.

3: What CLAPA Does

3.1: What is the Public Need?

- Around 1 in 700 people in the UK are born with a cleft lip and/or palate, making it the most common congenital craniofacial abnormality. Based on population figures, we estimate the number of people in the UK born with a cleft to be around 90,000.
- The condition will affect everyone differently, both physically and psychologically, and it requires complex medical treatment over 20 or more years.
- There is variation in services across the UK, with not all services meeting the proposed standards in the NHS National Service Specification and a risk that existing services will be eroded.
- Without CLAPA, there would be no independent organisation representing the needs of people affected by cleft in the UK, very few opportunities for people affected by cleft to meet and form supportive communities, and no direct supply of specialist feeding equipment for families in need.

3.2: Our Vision

CLAPA's vision is of a society where everyone affected by cleft lip and palate in the UK feels supported, connected and empowered wherever they are on their cleft journey.

3.3: Our Mission Statement

CLAPA works to improve the lives of everyone born with a cleft and their families in the UK by providing knowledge, practical support, a community and a voice for people affected by cleft.

3.4: Our Values

- **Community:** We believe the best way to support people affected by cleft is to bring them together to provide mutual personal support in an inclusive, accessible way.
- **Representation:** We are the leading voice of people affected by cleft in the UK, and will do everything we can to understand and represent their best interests.
- **Adaptability:** As the world changes, so will the best ways to improve the lives of people affected by cleft. We will use our limited resources to provide the most impactful, relevant support at the right time, based on the best available evidence.
- **Empowerment:** Everyone deserves to feel confident, informed and in control of their and/or their child's care. We uplift the people in our community to become advocates for themselves and others.
- **Integrity:** We work for the cleft community, and will be transparent in what we do and why.
- **Sustainability:** The cleft community deserves support they can rely on for years to come. We will build our services with long-term sustainability at their core.

3.5: Our Activities

3.4.1 Community

- Managing and creating new online and local **support groups** which help people affected by cleft to feel positive, connected, and in control.
- Managing and supporting a **network of volunteers** around the UK to provide opportunities for people affected by cleft to take control and help others, and to support local activities.
- Organising **local and national events** – from family days to conferences – which bring people together to promote knowledge, build confidence, and create communities.

3.5.2 Support

- Training **parent and patient volunteers** to provide **one-on-one support** at all points of the cleft journey.
- Providing **specialist feeding equipment** for babies born with a cleft with our Feeding Service, including supplying new families with free ‘Welcome Packs’.
- Maintaining a trusted and carefully-curated **website** that is a 24-hour, one-stop-shop for stories, photos, information and understanding for everyone in the UK cleft community.

3.5.3 Knowledge

- Our comprehensive, accessible, certified **information service** is led by the needs of our community and works in harmony with medical advice from the NHS. We will ensure information is available for all stages of the cleft journey in the most appropriate format.
- Supporting volunteers to **educate schools, local communities and healthcare professionals** about cleft lip and palate.
- Working to help healthcare professionals and the public to better understand the reality of cleft lip and palate in the UK by **raising awareness** of the issues that matter most to our community.

3.5.4 Empowerment

- Working to help people **take control** of their or their child’s cleft care and make well-informed decisions by promoting knowledge, understanding and positivity in the cleft community.
- Actively promoting opportunities to get involved with **research about cleft lip and palate**, and to collaborate with researchers to make their work accessible to the whole community.
- **Surveys and consultation groups** (such as the Children and Young People’s Council (CYPC), the Adult Representation Committee (ARC) and National Consultation Group (NCG)) will provide the charity and researchers alike with invaluable insight, and give our community a way to influence CLAPA’s work.
- Continue to develop our position as the well-respected **voice of people affected by cleft in the UK** by ensuring we have a presence on appropriate boards and committees looking to improve care.

4: The Next Three Years

The past six years has been a period of rapid growth for the charity, but as we move into a time of great financial and political uncertainty, CLAPA's focus over the next 3 years will be on preserving and consolidating existing services.

This will involve a re-evaluation of services and activities with reference to our core values and the expressed needs of our community. Our local and national support services will continue to make a tangible difference in areas of defined need, and we will continue to collect high quality data to help us evaluate and report on our impact.

The UK cleft community deserves high quality support services they can count on for years to come. This three year strategy will ensure CLAPA can continue to provide these services in a sustainable way even through financial difficulties, and will lay a solid foundation for carefully considered growth when we are ready in the future.

4.1 Objectives & Activities

The overall aim of the next three years is to consolidate and improve our existing services, with an emphasis on long-term sustainability for projects with the highest impact.

Rather than growth, we will work on "behind the scenes" improvements to the organisation as a whole, with particular attention paid to safeguarding, staff and volunteer wellbeing and the improvement of communications and fundraising pathways to support the charity's ongoing work in a changing world.

In these three years, we will work hard to get CLAPA to a stronger financial position, and to have developed a greater understanding of the limits of future fundraising growth given the size of our community and an increasingly limited pool of external funding. This will feed into future strategy and will help us ensure that any moves towards growth we make after 2021 are viable, sustainable, and appropriate within our values and vision.

4.1.1 Governance

At this uncertain time, ensuring effective governance and making use of the expertise of our trustees is essential. Over this period, we will:

- Fulfil or exceed all of our legal obligations and become an exemplar of best practice.
- Recruit, support and develop our trustees to ensure they feel valued, certain of their role, and supported appropriately. This will include an annual survey.
- Provide opportunities for staff and trustees to work together. This will include the use of dedicated committees of staff and trustees working to develop CLAPA at a high level around different areas.
- Work towards achieving the Charity Governance Code to ensure our governance is at the highest standard possible.
- Provide regular performance reports to both trustees and CLAPA staff to promote transparency and accountability.

4.1.2 Finance

Our current finance team inherited an unsuitable and outdated accounting system, and over the 2017/18 period have worked to modernise this. Once fully set up, this should allow greater transparency and ease of reporting. Moving forward, we will focus on the following:

- Getting our accounting system up to date and avoiding backlogs in the future.
- Developing effective financial procedures and reviewing our processes.
- Developing a fully responsive reporting system for all relevant stakeholders once our accounting system is up to date.
- Providing training to non-finance senior management staff to better equip them to engage with CLAPA's financial planning.

4.1.3 Staff & Management

CLAPA's growth has only been possible thanks to a team of passionate and dedicated staff, and to preserve our services up to 2021 we must look after our staff as a key resource. A focus on staff wellbeing will help CLAPA reduce turnover, foster a greater connection to our work, increase productivity, and create a more resilient charity better able to cope with the unique challenges of the next three years. Over this period, we will:

- Support line managers to embed this strategy in the day-to-day work of staff and to ensure goals and objectives are set which directly contribute to the fulfilment of this strategy.
- Implement the Staff Handbook and ensure it remains accessible and up to date.
- Ensure staff are supported, developed and appropriately rewarded for their efforts when this is financially viable.
- Establish an annual staff survey, and continue to work on any issues raised in a transparent and inclusive manner.
- Implement a wellbeing committee within the staff team and promote staff satisfaction as a key value.
- Provide a working environment which is suitable to staff needs, including reviewing the current office and the provision of alternative working practices to achieve an optimal work/life balance, and monitoring of workload concerns.
- Focus on improving internal communications, specifically to help home-based and part-time staff to feel fully involved. Wherever possible, remote access to meetings (and recordings of meetings) will be used to include home-based and part-time staff.
- Formally embed responsibility for Human Resources (and Health and Safety) within the CEO role. While it is not financially viable to recruit for a new role with HR expertise, we will still ensure we have exemplary, robust and compliant policies in place regarding all aspects of HR, including a Safer Recruitment Policy, and that these policies have a built in review. In this period we will also actively seek to recruit a Trustee with HR expertise.
- When such opportunities arise, work towards appropriate mechanisms/marks which demonstrate that we are an excellent employer.
- Invest in technology, whenever possible, to improve the productivity of our staff and to avoid frequently replacing cheap and/or unsuitable technology.
- Facilitate the use of volunteers to support paid staff whenever possible.

4.1.4 Fundraising

2018-2021 will see CLAPA navigating an increasingly difficult and uncertain political and financial climate. To survive this we will need to initially stabilise income and then grow fundraising in a sustainable, measured way by developing our existing funding streams and making the most of every opportunity that comes our way. Over this period, we will:

- Work to get CLAPA on a financially stable footing.
- Undertake cost/benefit analysis of fundraising activities and refine fundraising programmes as a result.
- Continue building a portfolio of community and challenge fundraising programmes which successfully engage our community of supporters.
- Where possible, maximise opportunities to develop relationships with corporate partners and high value donors utilising the networks of our Trustees and stakeholders.
- Embed fundraising throughout CLAPA's communications, and establish regular fundraising campaigns at set points throughout the year, e.g. World Smile Day.
- Work towards a greater understanding of the limits of CLAPA's future fundraising growth given the nature of our work, the size of our community and the continuing challenging funding environment.

4.1.5 Communications

CLAPA's communications channels are our "shop window" as a charity and are how we engage the cleft community in our work and values. Despite making leaps forward in the past few years, there are still areas in which our communications lag behind. We must work hard to keep up with this changing landscape, and use the opportunities presented by the next three years of consolidation to define our position in the cleft world. Over this period, we will:

- Remain compliant with GDPR and all other data protection regulations.
- Continue to develop our digital presence and pathways, and continue to source low/no-cost solutions where these continue to have a high impact.
- Maximise opportunities to raise awareness of cleft and associated issues when the issue is in the public eye (or when suitable press requests are made) to further establish CLAPA as the voice of people affected by cleft in the UK.
- Celebrate our 40th birthday with a published piece of work demonstrating the difference CLAPA has made since 1979, and the difference we hope to make for years to come.
- Maintain our compliance with the NHS Information Standard and continue to develop excellent information products focused on the needs of the cleft community.
- Focus on increasing the diversity of stories and photos used in all our publications to better represent the entire cleft community.
- Continue to work with researchers to promote their work to our community. Establish consultancy rates to charge when appropriate.

4.1.6 Volunteering/services

At the core of this three-year strategy is the need to continue delivering our award-winning, high-impact support services in a safe and sustainable way to ensure they remain accessible for years to come. Over this period, we will:

- Deliver evidence-based support services at a local level through named Regional Coordinators and Engagement Officers. These include running local activity and adventure days, family days, Happy Faces Support Groups, Events Groups, Patient Voices Groups, volunteer training and supervision, developing relationships with NHS Cleft Teams, running the Peer and Parent Support Service, and other frontline services that sit with this team.
- Ensure we have excellent safeguarding policies and procedures in place, that staff and volunteers are appropriately trained, DBS checked where relevant and that we are legally compliant.
- Support the work of the Adult Services Coordinator in their three-year project to research the needs of adults born with a cleft and recommend appropriate services, which will be implemented where appropriate and financially viable. This will coincide with an effort to expand the presence of adults born with a cleft in regional groups and as ambassadors.
- Deliver services for children and young people including residential weekends and young people's activity days and continue to develop an online community and bank of resources to provide support to a greater number of children and young people than our activities are able to reach.
- Create a Diversity and Inclusion Strategy to work towards expanding the impact of CLAPA amongst the BAME community and other hard to reach groups.
- Manage and internally develop our feeding service to ensure it can keep up with ever-increasing demand and rising costs. This will include a review of processes and regular reviews of prices.

4.1.7 Partnership

At a time when many organisations are struggling, there are opportunities for mutually beneficial partnerships to share learning and resources. Over this period, we will:

- Continue to grow and develop our partnerships with other charities, groups and services to facilitate the needs of our teams and to monetise the sharing of skills and best practise where possible and appropriate.
- Continue to remain involved as a liaison with the research community and sit on boards as appropriate.
- Develop opportunities for co-funded activities, joint funding bids and shared promotion.
- Develop opportunities for our staff to act as consultants and charge as appropriate.

4.2: Annual Operational Plans

This section sets out, in broad strokes, CLAPA's specific plans for the next three years.

4.2.1. Looking Back on 2017/18

Although the previous year was a time of change and uncertainty, it is important to note the many successes CLAPA saw in this time, including:

- Winning the Charity Impact Award Health Category
- An Organisational Strengths Review which has directly fed into ongoing strategy
- The recruitment of an Adult Services Coordinator in March 2018, following a successful funding bid made after an adults mini-conference in summer 2017.
- Three papers have been published and widely disseminated using our research into diagnosis of cleft lip and palate. This has coincided with several other papers being published which CLAPA was directly involved with as a partner.
- The recruitment of part-time Engagement Officers in four regions of the UK to support local activity and provide our community with a named member of staff advocating for their needs. A central regional administrator was also recruited to support this extra activity.
- A full review of CLAPA's historical Branch Structure, which has now changed to a more flexible Group structure.
- CLAPA's Youth Forward Community was established to provide under 18s with dedicated content.
- The implementation of new financial systems to improve efficiency and the internal transparency of payment schedules, including the repayment of volunteer expenses.

4.2.2: In 2018/19

- We will support the Adult Services Coordinator in planning a series of activities and events dedicated to gathering information about the needs of adults born with a cleft in the UK.
- With the current lease period on CLAPA's offices drawing to an end, we will investigate the benefits of moving offices and develop a plan to achieve this.
- We will undertake our first annual Staff Survey. A survey of Trustees will also be conducted. The findings of these surveys will be shared and discussed amongst the team to promote transparency as we work to improve CLAPA from the inside out.
- We will publish our first Annual Report by combining the Impact Report and CLAPA News.
- We will explore ways to enable trained Young Peer Supporters to provide personal support to young people born with a cleft in line with our strict safeguarding policies and advice from the Psychology Clinical Excellence Network (CEN) within the NHS Cleft Service.
- We will prepare to celebrate CLAPA's 40th anniversary with a look back at how cleft services and support has changed, and what our hopes are for the future.
- We will need to recruit three new trustees this year, and will also explore to opportunity of recruiting additional patrons.
- We will review the policies and procedures of our Feeding Service to ensure we can continue to keep up with rising demand and reduce time spent on customer complaints and queries as a result.

4.2.3: In 2019/20

- We will continue, where appropriate, the services and development work outlined above.
- This will be the third and final year of the current England Regional Coordinator Project. At this point we will review and plan for the future of this service.
- Our 40th anniversary will be a major theme of the year, particularly during Cleft Lip and Palate Awareness Week in May and on our anniversary date of 15th June (which we hope to celebrate with the launch of a cleft-focused Portrait Positive book).
- Where appropriate and financially viable, we will begin to implement the findings of the Adult Services Project.
- We will complete the review and re-launch of CLAPA's new-look information leaflets inspired by the needs of the community.

4.2.4: In 2020/21

- We will continue, where appropriate, the services and development work outlined above.
- This will be the third and final year of the Adult Services Project. At this point we will review and plan for the future of this service, including whether or not we will apply for further funding.

6: Managing Risks

6.1 SWOT Analysis

Strengths	Weaknesses
<ul style="list-style-type: none"> • Partnership and credibility with the NHS cleft teams • The only UK charity dedicated to supporting people affected by cleft • Quality of information – particularly website • Numbers and engagement of members • Community Giving fundraising • Strong community • Dedicated staff team • Excellent reputation with NHS, community and charity partners 	<ul style="list-style-type: none"> • Reliance on grant funding • Lack of diversity in membership • Legacy reputational issues • Medium charity size (ineligible for funding aimed at small or large charities)
Opportunities	Threats
<ul style="list-style-type: none"> • Increased emphasis on user/patient involvement in public and health services • Clearly defined “target” group of stakeholders • New media and social networking • Monopoly on bottle supply plus increased range • Revised branch structure • Partnerships/joint activities • Online fundraising opportunities 	<ul style="list-style-type: none"> • More competition amongst voluntary organisations for smaller pots of funding • Brexit risks to economy • Low opinion of the third sector at present • Lack of progression for staff members and risk of heavy workload • Ongoing impact of change to branch finance structure • Social media incidents