CLAPA
Cleft Lip & Palate Association

Ending the Cleft Dental Crisis

Foreword

For too long, people born with a cleft have faced barriers when trying to access something as fundamental as dental care. What should be routine has instead become a source of anxiety, frustration, and inequality. CLAPA has heard these stories for years from our community: adults turned away from practices, parents struggling to find a dentist for their child, and young people anxious about appointments because their needs aren't understood.

That is why we carried out our Dental Access Survey. We wanted to move beyond anecdote and bring together the real, lived experiences of people across the UK. The results are stark. Almost half of those who took part reported problems accessing dental services. Many spoke about dentists who lacked training or confidence in treating people with cleft. Some were even denied care altogether. These are not isolated incidents – they are symptoms of a system that is failing to meet its responsibilities.

Dental care is not a luxury. It is essential to health, confidence, and quality of life. Yet our community's experiences show that people born with a cleft are being let down. This must change.

This report sets out a clear plan for how we can put things right: improving access, training, care, and transparency across the NHS. It is rooted in evidence, shaped by lived experience, and guided by the expertise of clinicians and professionals who share our determination to act.

We are grateful to every person who shared their story and to the professionals who have helped us shape these recommendations. Together, we can end the cleft dental crisis and ensure that everyone born with a cleft can get the care they need, when they need it – for life.

Oliver Rendell
Chair of Trustees, CLAPA

Background

CLAPA is the UK charity for people affected by cleft. For over forty years, CLAPA has been at the heart of the cleft community: supporting people born with a cleft, connecting families, and now making sure their voices are heard in the corridors of power. We are led by the experiences of our community, and everything we do is about making sure those experiences shape services, policy, and practice across the UK.

A cleft lip and/or palate (cleft) is one of the most common congenital conditions, affecting around one in every 700 babies, that's 3 babies born every day. It happens when the structures of the lip and/or palate don't fully form during pregnancy. Surgery is needed in the first months of life, and care continues into and through adulthood. Living with a cleft can affect speech, hearing, and confidence – but one of the biggest and most persistent challenges we have heard about is dental health.

Dental health matters deeply to people affected by cleft. Teeth may grow differently, oral hygiene can be harder to manage, and specialist input is often essential. Children with a cleft have, on average, around one-third more teeth affected by decayed, missing, and filled teeth and adults with a cleft have, around, one-quarter more.

Getting the right care at the right time can make a huge difference to someone's health and quality of life. But too often, people in our community tell us they struggle to find dentists who understand cleft, access referrals, or to get consistent advice. Some are even turned away from services altogether because of their cleft.

Our community has again and again, they have raised concerns about barriers to dental care to CLAPA directly and we know to the cleft teams operating in the NHS. They have spoken about feeling isolated, being left to fight for services, and about the stress this causes at every stage of life.

This is why we carried out our Dental Access Survey we wanted to hear people's experiences in detail, to bring together stories and evidence, and to make sure our community's voice could not be ignored. The results confirm what we have long heard anecdotally: that access to appropriate dental care is not guaranteed, and that people born with a cleft are being let down by the system.

This policy paper is our response. It sets out what our community told us, why this matters, and how we can work together to put things right. Our aim is simple: to make sure that everyone born with a cleft can access dental care.

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1. https://research-information.bris.ac.uk/ws/portalfiles/portal/130909263/Revised_Paper_VW.pdf

Results of our Survey

In spring 2025, CLAPA began a UK-wide survey to better understand the experiences of our community, people affected by cleft, when trying to access dental services. This was the first survey of its kind, and it gave our community the chance to speak directly about the challenges they face, as well as what would make a difference.

Who responded to the survey?

A total of 432 members of the cleft community completed the survey from across the UK. Responses came from every cleft centre, with representation broadly reflecting the size of each centre's patient population.

- 52% of respondents were adults born with a cleft.
- 48% were parents, relatives, or carers of a child or young person with a cleft.
- Around two-thirds of respondents had a cleft lip and palate, while those with an isolated cleft lip or cleft palate were represented in roughly equal numbers.

This strong response gives us confidence that the results reflect the experiences of our community across the country.

What are the topline results?

The survey revealed widespread barriers to accessing dental services among people affected by cleft:

- 49% reported they had faced issues when trying to access local general dental services.
- 7% said they had been turned away or denied dental treatment because of their cleft.
- 42% reported problems linked to a lack of awareness, understanding, or training about cleft among dental professionals, leading to denial of care or inappropriate treatment.
- 38% said they had been unable to access dental services because of the cost involved.

To compare this data with markers for the general population we have used data from the most recent edition of the "Great British Dental Survey" by MyDentist.

What conclusions can we make?

Barriers to access are common

Nearly half of the cleft community have experienced problems accessing dental services, compared to just 28% of the general population who report being unable to secure a dental appointment.[2] This highlights a significant inequality that must be addressed.

Cost is a significant barrier

Over one-third (37.5%) of respondents had been unable to access dental care due to cost pressures. This is far higher than the general population, where around 16% of adults report avoiding dental care because of cost.[2]

Unequal access because of cleft

Most worrying of all 7.18% of respondents had been explicitly denied dental treatment because they were born with a cleft. This is unacceptable. People affected by cleft often have more complex dental needs and require greater—not lesser—access to appropriate care.

A lack of awareness among dental professionals

The single most common barrier raised by our community was poor awareness and training among dental teams. 41.7% of respondents said this had led to problems accessing care, including inappropriate treatment and, in some cases, outright refusal. This demonstrates the urgent need for mandatory training and better integration of cleft care within dental education.

2. https://dentistry.co.uk/app/uploads/2022/01/the-great-british-oral-health-report-2021.pdf

What we have done so far

CLAPA's survey and our dialogue with our community has made it clear that access to dental care is a serious and urgent issue. We knew we had to act. Since the survey closed, we have begun a programme of work to better understand what must change so that we can campaign to make sure that the experiences of people affected by cleft are heard at every level of the system.

One of our first steps was to bring together a **Dental Policy Working Group**. This group includes members of our community with lived experience of cleft, alongside cleft care professionals and other experts. Together, they have been meeting to discuss the results of the survey, explore the root causes of the problems, and identify the changes that would make the greatest difference. The group ensures that both professional expertise and the voices of those directly affected are at the heart of CLAPA's campaigning.

Alongside this, we have been engaging with a wide range of stakeholders including politicians, dentists, trade bodies and other charities to build a fuller picture of the challenges and opportunities. We have spoken with dental professionals, researchers, professional bodies, and policymakers across the UK. These conversations have given us valuable insights into the barriers within the current system and the levers for change.

We have also spoken to young people born with a cleft by speaking to the Children and Young People's Council and they have given us a great insight into the challenges faced by them when it comes to going to the dentist.

Through this process, a clear picture has emerged of the areas where action is most urgently needed. By combining the voices of our community with the expertise of professionals, we have identified five key areas for change which will guide our policy work and campaigning. These areas form the foundation of our vision for a system where everyone affected by cleft can access the dental care they need.

What needs to change

Through our survey, the creation of our Dental Policy Working Group, and our ongoing engagement with stakeholders, CLAPA has identified four key areas where change is urgently needed. These will shape our campaigning in the months ahead.

Improving Access

Everyone born with a cleft should have a guaranteed right to NHS dental care throughout their life. Our community has told us too often that access depends on postcode, cost, or whether a dentist understands cleft. This inequality must end.

Improving Training

A lack of knowledge and confidence among dental professionals is one of the biggest barriers faced by our community. Adequate cleft-specific training must be mandatory for all dental students that prepares them to properly treat all patients with cleft, with ongoing professional development available across the workforce.

Improving Care

People with a cleft need properly integrated care that recognises cleft as a lifelong condition. Multidisciplinary pathways – linking dentistry, orthodontics, surgery, and allied health professionals – must be consistent and accessible everywhere in the UK.

Improving Transparency

Too little is known about how people with cleft access dental services. The NHS must commit to regular monitoring and public reporting on access and outcomes for cleft and other priority groups, to drive accountability and ensure real progress.

The four areas of focus outlined above capture what our community and professional partners have told us matters most. But focus alone is not enough. To make real, lasting change, we need to turn these priorities into clear, achievable policy proposals that can shape how dental care is delivered for people affected by cleft.

Drawing on the lived experiences of our community, the expertise of our Dental Policy Working Group, and conversations with sector stakeholders, we have developed a set of recommendations that show exactly what needs to change. These proposals give shape to our campaign: they are practical, evidence-based, and rooted in the voices of those most directly affected.

Detailed Recommendations

CLAPA is calling for meaningful, practical reforms to ensure that no one in our community is left struggling to access the dental care they need. Our proposals are rooted in the lived experiences of families, children, and adults born with a cleft, as well as the expertise of clinicians and dentists who understand the unique challenges of cleft care.

We believe that these recommendations can deliver lasting change across the country and improve outcomes for every person affected by cleft.

1. Guaranteed NHS Dental Care Access for People with Cleft

- Cleft should be recognised as a priority lifelong condition within NHS dental services, ensuring timely and equitable access to care for everyone born with a cleft.

- The governments should commitment to ensuring that everyone born with a cleft has a right to NHS dental treatment, reflecting the additional and often lifelong needs of this community.

- Whilst reforming dental contracts, the NHS and governments should ensure that dentists are properly supported – not penalised – for taking on patients with complex needs such as cleft.

- The NHS should recognise cleft as a complex lifelong condition, that requires continued access to general and specialist dental input throughout adulthood.

- The NHS should strengthen multidisciplinary working across dentistry, orthodontics, surgery, and allied health professionals to provide joined-up cleft care.

2. Specialist Training & Workforce Development

- Dental schools should embed universal level standardised cleft-specific training into undergraduate curriculum.

- Professional regulators should mandate ongoing CPD on cleft and complex cases and monitor the uptake.

- The NHS should expand specialist training placements and support dentists to build confidence and capacity in treating patients with cleft.

3. Clear Care Pathways & Commissioning Oversight

- The NHS should work with cleft teams to ensure that nationally consistent care pathways for cleft-related dental services, including transition from paediatric to adult care.
- The NHS should name champions to push better access to dental care for the cleft community.

4. Involving the Cleft Community

- The NHS should involve people affected by cleft in dental service design, commissioning, and evaluation of the services they use.
- Professional bodies should work with CLAPA and people with lived experience to co-produce training materials and service and training standards.

5. Data, Monitoring & Accountability

- The NHS should begin national data collection on access and outcomes to dental care for patients with cleft.
- The health departments should commit to annual public reporting on dental access and waiting times for priority groups, including cleft.
- Local health bodies should monitor local performance and publish data to ensure transparency and accountability.

6. Public Awareness & Information

- The government should fund the production of clear, accessible, information for families on dental rights and entitlements for people with cleft.
- The NHS should commit to supporting raising awareness of cleft amongst dental professionals.
- The professional bodies should promote awareness among dental teams and the public to reduce stigma and ensure patients feel confident accessing services.

What we will now do

CLAPA will not stop until everyone in our community can access the dental care they need and deserve. Change won't come from policy papers alone: it will come from people power, lived experience, and a determined movement for fairness.

Making our voices heard amongst politicians

We will bring the voices of the cleft community directly to MPs, MSPs, AMs, MSs and Peers', showing them, why urgent change is needed and asking them to stand with us.

Challenging the NHS

We will campaign for cleft to be recognised as a priority within NHS dentistry, ensuring our community's needs are no longer overlooked.

Pressuring local decision-makers

We will make sure local decision makers feel the pressure to act. Nobody should miss out on vital care because of where they live.

Mobilising allies in the profession

We will work with dentists, professional bodies and training providers to demand better support and education, so that no dentist feels unable to treat someone born with a cleft.

Building a movement in the cleft community

We will share the evidence, stories and experiences that show why this matters. Families and individuals affected by cleft will be at the heart of this campaign, shaping the solutions and driving the change they want to see.

Holding decision-makers to account

We will track every promise, every commitment, and every step of progress. Where action falls short, we will shine a light on it.

This is just the beginning. Together, we will make sure that dental care for people born with cleft is not an afterthought, but a right that is guaranteed – wherever you live, and whatever your circumstances.

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