



investing in children

**Report on**

**The impact of a cleft lip and palate on a young person's life**

**John Harvey, Rachel Lawson, Michael Potter, Claire Potts,  
Rachael Stephenson**

Report by Pippa Bell

## **Introduction and brief**

**The impact of a cleft lip and palate on a young person's life**

**The impact of treatment for a cleft lip and palate on a young person's life**

**Comparison of Cleft treatment in the North East before and after the centralisation of services**

**Conclusions**

**Recommendations**

**Top Ten Tips – Advice for children and parents with cleft lip and palate**

Appendix – A detailed report of the new centralised cleft service at the Royal Victoria Infirmary, Newcastle-upon-Tyne

**Acknowledgments : We would like to thank David Landes, Eileen Stephenson, Ian Shaw, Leo Stassen and Julia Errington for all the help and support they have given us throughout this project.**

# Introduction

## The Brief

Following the decision to centralise the Cleft lip and palate services in 2002, David Landes (then consultant in Dental Public Health for the Co. Durham and Darlington Health Authority) commissioned Investing in Children to facilitate a group of young people with Cleft lip and palate in the Newcastle and Sunderland area.

The group's brief was to highlight the issues of a young person living with a cleft and to look at the new centralised Cleft lip and palate service from an adolescent users point of view.

## How the research was carried out

Over the past 2 years John Harvey, Rachel Lawson, Michael Potter, Claire Potts and Rachael Stephenson assisted by Pippa Bell have been meeting as a group. Between them the members of the group have experience of the cleft services at the Royal Victoria Infirmary, Newcastle and the Royal Hospital, Sunderland.

In order to identify the issues that are the most important to them, the group employed the following research methods:

- Discussion and 'think-tank' sessions as a group based around the group's personal experiences
- Visit to the new centralised cleft service at the Royal Victoria Infirmary, Newcastle-upon-Tyne.  
(See Appendix)
- Research on the world-wide web
- Interview of a younger cleft person

The findings, issues and recommendations that the group have made have all been drawn from this original source material.

The research has at times been very challenging and frustrating. Meetings with other cleft patients, which had taken time to organise, were often cancelled. A planned visit to the Leeds cleft service also had to be cancelled and was unable to be re-arranged. Therefore the following findings were prepared within these limitations.

## The Findings

**The psychological impact of having a Cleft lip and palate on a young person's life.**

***'The worst thing about a cleft lip and palate is that people stare at you and other kids tease you because you look different'***

This quote from a member of the group accurately sums up how it feels to live with a cleft lip and palate. Each member of the group had had very similar experiences in their earlier lives and from their discussions about these shared experiences came the following issues.

- **Bullying**

The young people had all experienced bullying and teasing at school by their peers due to the fact that they look different and 'ugly' and some of them also had speech impediments and had trouble communicating with others. Before they had started at school the young people had been protected from other children's jibes and they had not been aware that they were different from their friends. Bullying is a major issue for a young person with a cleft; it shapes the rest of their lives and leaves them with feelings of vulnerability and lack of confidence.

- **Vulnerability**

*'People stare and this makes me feel vulnerable'*

All the young people had experienced feelings of vulnerability because they look different even when their cleft is repaired. Often unpleasant attention increases after operations because of the swelling and scars on their faces as they are healing. The stares have not stopped as they have got older, although fewer adults stare than children. As they have grown the young people have developed ways of learning to cope with their feelings of vulnerability.

- **Lack of confidence**

Due to teasing and bullying the young people have been left with feelings of shyness and in some cases low self-esteem. In some cases additional communication problems, have meant that the young people have often been unable or reluctant to stand up for themselves when being bullied. Some feel that certain careers where leadership qualities are needed are not open to them, as they perceive this would leave them open to criticism about their looks and speech impediments.

- **Isolation**

*'Looking different'* and finding it difficult to communicate - sets young people with cleft apart from their peers. Learning to cope with the bullying has often left them feeling isolated. They all said that they had learnt to pick their friends wisely. One member of the group felt that if they hadn't been born with a cleft that they would now have more friends and more opportunities.

- **Media's view**

The young people felt that the media promotes an unfair image that in order to be successful means you have to be beautiful and conform to an image of physical perfection. Although they acknowledge that this is a very superficial view, nevertheless this notion of society adds more strain to a young person growing-up with a cleft lip and palate. Frequently in the media the 'baddie' or idiot (eg. Sam Dingle in Emmerdale) is portrayed with a handicap and sometimes with a cleft and this image re-enforces the public's image that having a cleft is somehow bad or evil or stupid.

## **The impact of treatment on the lifestyle of a young person with a cleft lip and palate**

The young people raised the following issues about their medical treatment. These are the issues, which have the biggest impact on the life of a young person with a cleft.

- **Operations**

Drawing on their own experiences the young people feel that it is better to have the major cleft repair operations done at the earliest possible age, because:

1. **Looks**-When the operations are done at an early age the scarring will be minimised and the wounds will heal quickly.
2. **Embarrassment** -If the operations can be completed before the young person reaches adolescence, they will be less self-conscious and embarrassed about their disfigured looks while they are recovering.
3. **Inconvenient** - Some post-operative care can take up a lot of time and the young people don't want to miss too much school work or time off from their job as they get older.

The group all felt that there was one draw back to having operations performed at an early age. Namely that younger children are more likely to inadvertently open their scars through falls or rough play and this would therefore involve a return visit to hospital to have the scar re-sewn.

- **Communication**

1. **Fear** -*Your relationship with your surgeon is very important because you have to trust them'*  
One of the biggest issues facing a young person with a cleft is how staff treat them. They felt that all medical staff who treat them should be able to communicate with them on their level. This engenders a trusting relationship between patient and staff and gives the young person faith in their medical team and their ability to repair their clefts.  
Unfortunately some members of the group had suffered experiences when staff had failed to talk to them on their level. This has made the treatment of their cleft a much more frightening experience.
2. **Inclusion**- *'I felt like a ghost'* commented one member of the group as they remembered a discussion about treatment between their parents and medical staff that had excluded them. Those patients who had not been involved in discussions about their cleft operations had suffered greater anxiety over their treatment. However some of the group who had been included in these discussions said that this had created a feeling of respect between staff and patient, and had helped them to cope well with their operations.
3. **Information**  
The group felt that they had not always been given enough information about the treatment they had to undergo and the results of the treatment. They would like as much information about their medical procedures as possible because:
  1. **Anxiety**-The young people want to be prepared for how they will feel and what they will look like (within reason) after their operations. This will reassure them and take some of the anxiety out of having to cope with a lot of operations.  
The young people would like to know the people who are treating them so that they can begin to build a relationship based on trust with the cleft team. They would also like to know where they are going to be treated; being treated in a familiar environment will help them to feel more secure.
  2. **Preparation** -They can prepare their family and friends for how they will be feeling and what they will look like after an operation. This encourages their feelings of self- confidence and their ability to deal with people who think that they *'look funny'*.
  3. **Choice** –some young people have felt that they were unable to make an informed decision about their treatment, because the medical team had not given them choices. Therefore they had felt that they were being pushed into treatment that suited the medical team rather than themselves.

# Comparison of Cleft treatment before and after the centralisation of the cleft services

## BEFORE

**Cleft treatment** took place in the nearest hospital to the young person's home

**The Cleft team** consisted of the Oral and Facial surgeon, Ear nose and Throat surgeon, Cleft Liaison nurse, Orthodontist, Speech and Language therapist, Paediatrician and Photographer.

**Waiting Room** – there were some toys for young children in the waiting area in Newcastle and Sunderland hospital but nothing for adolescents to amuse themselves with.

**Communication with medical staff** – Communication between the staff and young people varied from hospital to hospital and from one member of staff to another. In one hospital the young person felt like a '*ghost*' no one acknowledged their presence. In another hospital the young people felt included in decisions and their opinion was valued even from an early age.

## AFTER

Cleft treatment takes place at two centralised locations in the north of England – Leeds General Infirmary and Royal Victoria Infirmary, Newcastle-upon-Tyne. The area these two hospitals cover is from the river Humber in the south to the river Tweed in the north and to the West Coast of Cumbria.

The cleft team consists of Oral, Facial surgeon, Ear Nose and Throat surgeon, Paediatrician, Orthodontist, Speech therapist, Nurse manager, Cleft liaison nurse specialists, Psychologists, Geneticist and Photographer.

The waiting area in Newcastle has toys for younger children and nursery nurses to help amuse them if there is a long wait. There is also a separate area for adolescents where there are computer games for them to play on.

The cleft team view communication with young people as a vital part of the treatment process. They are all encouraged to build a good relationship with the young patients and to communicate with them at their level. From an early age the young people are encouraged to take part in decisions about their treatment, and in early adolescence they are able to decide which treatment they would like. If at any point they decide that they don't want an operation it would not be forced on them, but this would not mean that they couldn't change their mind about having the operation in the future.

**Unapproachable staff** – In the past cleft clinic appointments have been a very anxious time for some of the young people. In one case the young person had been confronted with four members of a cleft team sitting behind a desk discussing their cleft treatment. They had felt that *'It was more like an interview, than something for my benefit'*

**Operations** – Before the operation the young people were allowed to visit the hospital and ward to see where they were going to have their operation.

Some young people were lucky enough to have surgeons who talked them through the operations they were about to have. One young person who felt they weren't being listened to and anxious about the outcome of an operation drew a picture to show the surgeon of how they wanted their repaired nose/ lip to look.

**The ward-** the young people were in a general Ear, Nose and Throat ward with young children. There were toys and amusements for the younger children but nothing for the adolescents.

**Post Operations-** after an operation in Sunderland the parents were able to stay in hospital with the child. In one case in Newcastle the mother was not allowed to stay with her child. The young person was very distressed and still remembers their hospital stay as a traumatic experience.

The young people have fewer medical staff present at their consultations now. The consultations take place in an informal setting, which is more relaxed. If more medical staff need to be present then the room has a two-way mirror so that the consultation can be observed without over-crowding the young person with medics.

All the cleft team staff are on first name terms with the young people apart from the surgeon.

To appeal to younger patients and to look less formal, the surgeon in Newcastle wears Disney bow ties.

The young people are allowed to visit the hospital to see the ward and to meet the nurses. If the young person lives too far away and it is not easy for them to visit the hospital then they don't have to go. The cleft team that they see regularly in their area is based at the hospital where the operation will take place so the young people will see familiar faces before and after their operation.

The operation and its implications will be discussed with the young people and their parents beforehand.

The young people all stay on a maxillo-facial ward with other patients of their own age. There are a number of individual cubicles available for teenagers or long-stay patients use. There is also access to computers for adolescent patients.

Parents are allowed to stay with the young people in a chair bed on the ward or in a hostel for families next to the hospital in Newcastle.

**Information** – In the past the young people have not been given the opportunity of meeting someone with a cleft of their own age with whom they can talk about their treatment and share their experiences.

**Communication between members of the medical staff** – In a case known to the group the wrong operation was performed on a young person because of communication problems between cleft team members.

**Follow-up appointments**- If the young person needed to see a Dentist for unrelated dental work or an Ear specialist the hospital would try and arrange for them to be seen by the relevant members of staff when they came for their cleft clinic appointment.

When a baby is born with a cleft the cleft team will offer to put the new baby's family in touch with a 'Link family' who have already have a cleft child. The 'Link family' offer support, advice and friendship to the new baby's family.

Members of the cleft team are informed about decisions concerning a young person's treatment if it involves their speciality. The young person is also informed about which member of the team will be dealing with their treatment. As the cleft team are all based at one hospital communication errors between team members happen less frequently.

If a young person needs to see other medical staff about cleft related problems then the cleft team will arrange these appointments so that they run consecutively at one appointment time. Specialist staff are often on standby to see young cleft people when the regular cleft clinic is held.

## Conclusions

The group had had many concerns about the new cleft lip and palate service before they undertook their research and discovered exactly what the new service had to offer. Using their research findings they have been able to compare the new centralised cleft service with the service and treatment they have received in the past (see above) and they have drawn the following conclusions.

Through their research and the comparison with the old cleft service the young people have realised that the new service has already addressed many of the problems they had encountered in the old service. For example:

- All young people with a cleft are now being included in decisions about their treatment from an early age.
- Parents of cleft patients are now always able to stay with the young person in hospital whilst recovering from an operation.
- The cleft team are now giving the young people more information and more options about their medical treatment.

Through their research the young people also discovered that many of their worries about how the new centralised cleft lip and palate service would work were unfounded. For example they had been concerned that:

- Frequent travelling to and from the centralised hospital for treatment would be inconvenient and expensive for the patient and their family.
  - Instead they found out that the cleft team visit the family at home or in their local hospital to cut down on a lot of travelling for the family.
- Post-operative care for cleft patients would be held at the centralised hospital where they had had the operation.
  - The group have learnt that the cleft team are able to supervise post-operative care in their local hospital.
- If they were going to be operated on at a hospital far from home, they wouldn't know any of the staff at the hospital.
  - The group have found out that the cleft team is based at the hospital where the operations take place so they will know the cleft personnel who are treating them.
- They may have to endure a long stay in hospital in a general children's ward.
  - Instead they found out that as an adolescent they will be given their own cubicle on the ward set apart from younger children, and for entertainment they will also have access to a computer.

The young people were impressed that many of the issues that are important to an adolescent with a cleft lip and palate have been successfully addressed.

However there are other issues which haven't been dealt with and the group's suggestions for these are found in their recommendations.

## Recommendations

These recommendations have come from the group's collective experience of having a cleft and their research into the cleft service.

### **New centralised cleft lip and palate service**

**Information about the new service-** The group would like all Cleft lip and palate patients to be given information about the new cleft service. Through leaflets in their present clinic, a video presentation in their current waiting area or group presentations. In particular they would like the information to address their past anxieties such as travelling a long way to an unknown hospital, and being seen by unfamiliar staff (see conclusions). This will then take some of the fear of the unknown out of the new service for any young people who may use it in the future.

**Ward and waiting area-** The wards that the adolescents are admitted to need to be teenager friendly and to provide entertainment for adolescents as well as young children. This is already happening in the Royal Victoria Infirmary in Newcastle. If the ward has a relaxed and homely atmosphere then the patients recover more quickly!

**Communication with medical staff-** The young people would like all medical staff to engage with them on their level in a non-patronising manner and to talk about medical issues in language they can understand. They would like as much information as possible about the treatment that they are to receive and its outcome. They would like to be involved in decisions about their care and would appreciate guidance when deciding on a particular treatment. The group would like to build a relationship with all members of the cleft team which will help them feel reassured and confident during their long-term treatment.

**After an operation-** The group believe that it is important for a young person undergoing an operation to be prepared how they will feel and look after and operation. They will then be more able to cope with the tiredness and swollen features.

**More surgeons-** The group would like more surgeons available at both Newcastle and Leeds so that children and young people are not delayed in having their important facial operations. If a young person has an operation at an early age the scars will heal more quickly and therefore be less noticeable. If more surgeons are available then operation waiting lists will also be reduced.

**Psychologists** –The group liked the idea of psychologists being on the cleft team but they don't like the title psychologists it has connotations of people with mental health and would put them off using this service. Perhaps the title of the position could be changed to 'Advisor' or 'Tutor'?

**Mentor** – The group would like the cleft service of CLAPA to give young people the opportunity of being put in contact with a cleft person of a similar own age who has had experience of cleft and its related problems. This would help young people with feelings of isolation. The cleft team already offers a newborn baby's family a link family and the mentoring role could lead on from this.

## **Information**

**Internet-** CLAPA (Cleft Lip and Palate Association, a voluntary organisation for cleft patients and their families) has a website and on this there is a chatroom for adolescents. Here young people can talk to others who have had similar experiences to themselves. The group would also like to see more factual information for teenagers on the website because not every one wants to use a chat room and talk to strangers.

**General advice-** The group would like more information for teenage cleft patients covering adolescent issues to be available. Parents of new- born babies are given advice on how to help the babies feed etc. so general advice at any age is welcome to a cleft patient.

**Raise awareness in school-** While the child with a cleft is away from school the teacher could explain to their fellow pupils how difficult it is for that child to endure so many operations, and to have to spend so much time away from school and their friends. The other pupils could also be asked how they would feel if they had to have so many hospital visits and operations. As their knowledge about cleft grows the other children may become more understanding and respect the cleft child more which would help with issues of bullying.

**Raise awareness with the public about cleft** – Sadly society and the media's view is that to succeed in life you need to conform to an image of physical perfection. Cleft is often erroneously viewed as a disability. The group would like to challenge this view by raising awareness of what a cleft lip and palate is by a campaign in the media. Successful people with cleft or facial disfigurements could be used as role models (Actors, Lawyers, Politicians, Sports stars and Journalists) to show that cleft does not stop anyone achieving what they want. Perhaps CLAPA could help with a campaign such as this.

## **TOP TEN TIPS FOR HAPPY LIVING!** **(Or Advice to young people with a cleft and their families)**

1. Self-esteem – *‘We feel we’re unique not different’*  
-Take every opportunity to build up your child’s self-esteem. Focus on the things they are good at e.g. Running or art or maths!
2. Communication-*‘Talk to your family and friends about what it is like to have a cleft, help them understand’*  
-Let your family and friends know how you are feeling. Tell them if you are worrying about some treatment or if someone is bullying you at school.
3. Mentor- *‘Only another cleft person can really understand how I feel at times’*  
-Ask to be put into contact with other young people or children with a cleft so you can share your thoughts and feelings.
4. Awareness- *‘I think the kids at school teased me because they didn’t know how I was feeling’*  
– Encourage the teacher to talk to the class when the cleft child is absent about their visits to hospital and operations and ask them how they would feel in their place.
5. Information-*‘ Sometimes I worry about my treatment and how I will look afterwards’*  
–Get as much information about your cleft and treatment as you can by asking your cleft team, looking it up on the internet and talking to other cleft patients. This will reassure you and take some of the anxiety when having an operation.
6. Friendship – *‘Pick your friends wisely, true friends don’t see the scars’*  
-If you have good friends at school and home who like you for the person that you are, this will give you self-confidence and also allies on the occasions when people stare or tease you.
7. Trust- *‘I trusted my surgeon because he told me exactly what he was going to do’*  
-Build a good relationship with your cleft team so that you can be reassured that they have your best interests at heart and will give you the best treatment.
8. Time- *‘After an operation take time to recover and don’t wear yourself out’*  
-Don’t underestimate how long it takes to recover after an operation, don’t go back to school too early and be aware that the scars will take some time to heal successfully.
9. Equality-*‘Mum and Dad have always treated me the same as my brothers and sisters’*  
-Don’t give the child with a cleft more attention or special treatment. This will only emphasise their feelings of being different, and they want to be treated the same as everyone else, after all ‘ you’re just a normal person underneath your cleft’
10. Embarrassment- *‘I wish I had known that if I ate rice it could have come out of my nose!’*  
-Each person with a cleft is an individual and every case is different, but if you are aware of some of the problems that could cause embarrassment you can avoid them when you are with other people.