

# CONTENTS

Introduction	Section 1
Summary	Section 2
Profile of the Children	Section 3
The Diagnosis and Breaking the News	Section 4
Contact with the Surgeon	Section 5
Feeding	Section 6
The Hospital Stay	Section 7
The Cleft Team	Section 8
Contact with CLAPA	Section 9
Reflections and Additional Comments	Section 10

THE CLEFT LIP AND PALATE ASSOCIATION

REVIEW OF CURRENT TREATMENT

FOR YOUNG CHILDREN WITH

CLEFT LIP AND PALATE

JUNE 1996.

## 1.0 INTRODUCTION

- 1.1 CLAPA has been invited onto a committee set up by the Clinical Standards Advisory Group to study current treatment of cleft lip and palate. In order to ensure that CLAPA's contribution accurately reflects the experiences and opinions of parents, a postal questionnaire survey was undertaken.
- 1.2 Ninety eight questionnaires were sent out, and one hundred and three returned, the additional five being accounted for by the excellent networking arrangements of members of the organisation who are regularly in touch with each other and passed copies on.
- 1.3 A return of 100% may well be unique for a postal survey, most organisations would see anything between 11% - 14% as being satisfactory, with anything above as being good. It is difficult to know what prompted this incredible response. It may be that as most parents were satisfied with most services they wished to express this, and at the same time highlight those aspects of the services that were less than satisfactory, or it could be that they wanted to assist CLAPA, an organisation they genuinely hold in high regard.
- 1.4 This report seeks to accurately reflect the very many comments made by parents in all sections of the questionnaire. Where possible the parent's own words have been used as they provide a powerful testament of their experiences and feelings. Every effort has been made to report the positive experiences as well as those of a negative tone. However if services are to improve it is important that dissatisfactions are recorded.
- 1.5 Most of the questions have been analysed separately, cross linkages have only been made where it was possible to substantiate doing so. Parents were not asked to indicate which Health District they lived in, so it has not been possible to judge whether dissatisfaction levels are equally spread across the country. A number of parents did name their Health District mainly to complain about the lack of services, their comments have been recorded but not attributed.
- 1.6 The quality of responses to all questions was extremely high, with parents recounting their experiences in a lucid and helpful manner.

## 2.0 SUMMARY OF MAIN FINDINGS

- 2.1 Most parents were satisfied with most services. Concerns related to lack of information, and at the lack of staff knowledge and training in the care of cleft children, particularly feeding and pain control. There was some evidence of poor coordination of services and a lack of communication within departments and between other services. Concerns were expressed at the lack of continuity of care; staff shortages; and the length of time taken to fill vacant posts.
- 2.2 One in three parents was unhappy with the way they were told about their child's cleft. They considered some staff to be insensitive and lacking in understanding of the impact this news would have. There appears to be very little counselling available to parents at this crucial time.
- 2.3 Throughout the service there was a lack of up-to-date information on clefts and their treatment. Few hospitals had "before" and "after" photographs.
- 2.4 One parent in ten expressed dissatisfaction with the way their child's cleft had been diagnosed.
- 2.5 More than 40% of parents did not meet the surgeon who would repair the cleft until the first cleft clinic appointment, but nine out of ten were pleased with their first meeting with the surgeon.
- 2.6 Two thirds of all mothers achieved successful feeding patterns mainly by hit and miss methods. One third experienced considerable anxiety, caused mainly by the lack of suitable feeding bottles and teats on wards; staff ignorance of feeding cleft babies; and the lack of written information.
- 2.7 Eight out of ten parents were satisfied with their stay in hospital at the time of their child's operation. There were concerns at the lack of aftercare, and staff shortages. There was little or no information available on some wards, and some had poor facilities and a lack of privacy.

- 2.8 One in two parents had concerns regarding pain control. Staff appeared to have little knowledge or understanding of the way young babies experience pain.
- 2.9 Nine out of ten parents were pleased with the care they received from their cleft team. Concerns were based on regional differences where these were identified; and quality rather than quantity. There was a lack of specialist speech therapists and health visitors. There were concerns at cancelled appointments, long waiting times, and a lack of communication between departments and other services.
- 2.10 All but three parents were delighted with CLAPA and valued the service it provided.

## 2.11 ACTION PARENTS WOULD LIKE

- More and better information in all hospital maternity units for staff and parents
- Better training for all staff in all aspects of caring for cleft children
- More assistance with feeding, and the provision of a range of suitable bottles and teats on all maternity wards, and training for staff in their use.
- Research into breast feeding and clefts.
- Better liaison between departments, and between services
- Better training of staff in recognition of clefts during ultrasound scans.
- Training for staff in "breaking the news" and access to counselling for those parents who wish it.
- More specialist health visitors and speech therapists
- More privacy for all significant discussions with professionals

### 3.0 PROFILE OF THE CHILDREN

The intention of the study was to survey children of three years and under. Questionnaires were returned for 104 children, two were removed from the study as they were well outside the age range one being over 5 years, the other 18 years. Four other children were over 3 years old but under 4 years, these were left in the study leaving a total of 102 children.

#### 3.1 Represented in the study 38 girls 64 boys

Ages girls	under six months	4
	6mths - 12 mths	4
	12 mths - 24 mths	14
	24 mths - 36 mths	16
Ages boys	under six months	5
	6 mths- 12 mths	13
	12 mths - 24 mths	20
	24 mths - 36 mths	22
	over 36 mths	4

#### 3.2 Parents description of cleft

Type of cleft			
Unilateral cleft lip only	total	12	[ 4 girls 8 boys ]
Bilateral cleft lip only	total	3	[ all boys ]
Unilateral cleft lip and palate	total	40	[ 11 girls 29 boys ]
Bilateral cleft lip and palate	total	18	[ 6 girls 12 boys ]
None specified lip and palate	total	4	[ all boys ]
Cleft palate	total	25	[ 17 girls 8 boys ]

#### 4.0 THE DIAGNOSIS AND BREAKING THE NEWS

##### 4.1 [Q2a] How was your baby diagnosed and when ?

Of the 102 children in the study

80 diagnosed at birth or just after - 15 through scan - 5 no reply - 2 later

##### [Q2b] Who first told you about your babies condition ?

	Satisfied	Not Satisfied
<b>At birth</b>		
39 midwife	24	14 [1 n/r]
17 pediatrician	13	4
12 delivery team	5	7
8 self/husband	5	3
2 consultant	2	
1 orthodontist	1	
3 ward nurses	2	1
1 geneticist	1	
2 not recorded		
<b>At scan</b>		
6 radiologist	3	3
4 consultant	3	1
2 gynaecologist	2	
2 obstetrician	1	1
1 professor		1
<b>Later</b>		
1 consultant		1
1 ENT specialist	1	

#### 4.2 RECEIVING THE NEWS

4.3 One in three parents were unhappy with the way they were told about their baby's condition, no one section of the profession or level of seniority comes out better than others, although parents of babies in special units fared better.

4.4 There would appear to be no protocol within the Health Service for breaking distressing news to parents, and little evidence that staff have had any training in this area. Current practice indicates whoever happens to be present when the condition is discovered takes it on themselves to undertake this task, regardless of the quality of their interpersonal skills or their knowledge and understanding of the condition.

4. 5 Giving and receiving distressing news is never easy and it might be thought that message and messenger became confused and judgements clouded. While many parents referred to the shock at being told of their child's condition, there was much evidence that they were well able to separate the unwelcome news from the manner in which it was delivered.

4. 6 Parental satisfaction and dissatisfaction centred on five main areas

- staff attitudes and behaviour
- the quantity and quality of the information
- the professional's knowledge and understanding of the condition
- the accuracy of the diagnosis
- the level of support available

#### 4. 7 Staff attitudes

Staff attitudes and behaviour were significant in how parents received the news. Staff who were abrupt and insensitive in their behaviour or just left parents to get on with it, added to the stress parents were already experiencing. Where staff could empathise with the parents and handled the situation sensitively, parents were far more likely to deal with their shock. There were numerous examples of good and bad ways of breaking the news as the parents own words testify.

*"The delivery nurse took him away, and then just dumped him on me saying he has a cleft, someone will be in to see you..... it was two hours before they came"*

*"I was told that the baby had a cleft and at least he was a boy and could grow a moustache"*

*"The midwife seemed embarrassed and knew nothing about clefts and covered the baby's face with a blanket, this is the only photograph we have of our child's birth "*

*"I was anxious about the scan, as I had lost a baby at..... the radiologist went to get the professor, he offered me a termination"*

*"Unfortunately that day it was not my obstetrician and so the doctor did not perceive the impact of the news "*



#### 4.8 Information

The quality of the information had a direct correlation to the parents ability to cope with the shock of the news, Approximately one third of all respondents [36] commented on the quality of information at this stage, although it would be a recurring theme throughout this study. Six had positive experiences the remainder being negative. Complaints ranged from, too little - too late - too fast - out of date - information given in an unhelpful way [eg. explanations which were unclear and did not address parental concerns or just being handed leaflets ] Many complained there was little or no written information, others would have liked before and after photographs.

*"I just sat and cried for hours [ and days] I think if leaflets or books had been given to me at his birth I may have been able to come to terms with it sooner"*

*"The CLAPA files shown to me in hospital were twenty years out of date, they made me cry and feel depressed rather than reassured"*

#### 4.9 Staff knowledge

Parents felt reassured by staff who appeared competent and confident. This allowed them to deal with their feelings at being told the news, and concentrate on the immediate care of the baby. They were more inclined to be less concerned with the future at this stage knowing they would be well supported.

*"Mr..... was marvellous in the way he told us we were reassured and felt confident"*

*"I was told my baby would not survive... the doctor said he would refer my baby to another hospital and left"*

Staff who lacked knowledge not only denied parents vital explanations to help them understand and cope with the situation, they placed the onus and burden on the parents of making the choice of seeking out adequate explanations, or dealing with the immediate situation. This added to the stress parents were already experiencing.

#### 4.10 Diagnosis

One in ten of all respondents were unhappy with the manner of diagnosis. 4 were not picked up during an ultrasound scan [2 were seen but not recognised 1 being a trainee radiologist] - 2 were given incorrect diagnosis - 7 were not recognised at birth [1 as late as seven months]. In all cases of late diagnosis parent's gut feeling that something was wrong, and their concerns about feeding problems were ignored.

*"I can not stress enough the misery that the lack of diagnosis at birth has caused me and my family. I truly believed I was losing my mind, no one seemed to care that I felt instinctively that there was something wrong, my daughters feeble attempts at breast feeding and continual passing of fluids through her nose were surely signs which the midwives at least should have noticed"*

*"We were appalled at the lack of knowledge of the paediatrician, seven midwives, our own GP and the special care midwives. No one believed me that there was something wrong, I was regarded as a neurotic first time mother"*

*"I feel disappointed that three scans failed to pick it up"*

#### 4.11 Support

Only two parents actually mentioned the lack of support at this early stage, referring to support for their husbands who had the difficult task of breaking the unwelcome news to them. There were however other indications of the lack of support

*"I was too tired at the time, but I feel that they should have given my husband more support, he was just left alone"*

## 5.0 CONTACT WITH THE SURGEON

Over 40% of children did not see the surgeon until their first visit to the Cleft Clinic, thus many of the statistics and comments here also relate to question [5a.] which has not been analysed separately

### 5.1 [Q 3a] *How soon did you see the surgeon who would repair the cleft*

Birth/ before birth/	- 40
within days	
1 -2 wks	- 16
1 mth	- 14
2 mths	- 14
3 mths	- 12
4 mths or more	- 3
n.a	- 3

### 5.2 [Q3b] *Were you happy with the visit ?*

5.3 Approximately nine out of ten parents were pleased with their meeting with the surgeon and the cleft team, most being fulsome in their praise, "reassuring" - "confident" - "realistic" "was kind and understanding" "good explanation" "lots of opportunities to ask questions" "it was good to meet the whole team" were phrases that came up time and again. However there were several who although they had expressed satisfaction with the meeting, they nevertheless felt overwhelmed by the number of people present, and intimidated at asking questions.

*"Surgeon was helpful with the information he gave us, and very realistic in his approach"*

*"Very helpful and caring .... had time to discuss.... It was good seeing the whole team together"*

*"Visit highlighted the future treatment that will last for years, for the first time"*

*"Was able to enlighten us far more than anyone else his visit reassured us.....and gave us confidence in the future"*

*"At last people could help us by explaining the condition and provide a plan, the shock was lessened by having a team of professionals who could answer all our questions "*

*"Very reassuring, but we would like to have seen him in the twenty weeks of waiting" [ Baby diagnosed at scan]*

5. 4 Parents who found this first meeting less than satisfactory cited a number of reasons for their dissatisfaction.

\* seeing the wrong surgeon

\* lack of privacy

\* insufficient time and feeling rushed

\* too many people and not knowing who everyone was.

\* missing the opportunity to have all their questions answered

*"A little bit overpowering, a room full of people short time, not sure what questions to ask"*

*"I felt intimidated because there were so many people in the room, also there was a long wait, and I felt that they were so busy that they could not get rid of you fast enough"*

*"He didn't explain what he was going to do at all ..... we didn't know what he was talking about..... he was only there two minutes "*

*"We were on an open ward with a lack of privacy, aware of people at the next bed who could hear everything "*

*"We did not see the surgeon who would carry out the operation, we were passed from pillar to post"*

*"It was in a packed venue, everybody was rushed, I was apprehensive and overwhelmed, we were in a busy corridor, everybody was listening the whole procedure was dreadful"*

*"Should have seen the surgeon at birth not three months later"*

*"Waiting two hours..... a room full did not know who they were later learned they were the cleft team..... only five minutes "*

*"Not able to make most of it regarding questions, still in shock."*

*"Hard to take in so much at once"*

*"It all went over my head"*

5. 5 The visit of the surgeon seems to mark a significant watershed in the parent's acceptance and understanding of their baby's condition and what the future holds. The quality of the information provided; the realistic approach; the explanation of the ongoing procedures and plans; plus the opportunity to ask questions; all serve to reassure parents and give them confidence in the future.
5. 6 It is tragic that this visit came so late for many parents, especially those parents who had been unhappy with the original way the news was told. A total of 17 parents nearly two in every ten came into this category, five had to wait 2-7 days; seven 3 to 5 weeks; four 6 to 8 weeks; one had to wait a full three months. One parent who had to wait three weeks had been told her baby would not survive.
5. 7 For some parents the meeting with the surgeon came too soon, they were still in shock, and could not gather their thoughts together to ask the right questions, or were unable to take in the information they were given. They considered it to have been a lost opportunity.

## 6.0 FEEDING

*[Q4a] How soon were you taught to feed your baby and by whom*

### 6.1 ESTABLISHING A FEEDING PATTERN

- 6.2 Nearly two thirds of all mothers and babies achieved successful feeding patterns, even if it was a case of hit and miss. The difficulties experienced by the remaining third fell into two categories in equal proportion, lack of advice and lack of equipment.

*"Feeding was the most upsetting side of the early days as no one on the ward had any experience of cleft babies ..... the special care unit had tried but it was five days before he was feeding properly"*

- 6.3 Feeding caused considerable anxiety, especially when babies lost weight while yet another method was tried. Parents were concerned that there was a lack of advice on breast feeding, which meant that some mothers who would have liked to have tried breast feeding were discouraged, while others were pressured into breast feeding thinking it was successful when clearly it was not. One family wrote an anguished feeding diary, which showed ever lengthening feeding times until it took up the whole day at the rate of 1oz. per 2 hours. They finally undertook a sixty mile journey to receive advice on winding.

- 6.4 Advice was lacking on the different type of feeding bottles and teats. Parents who fared best were those in health districts where a specialist health visitor was employed, or where parents were put in touch with another CLAPA parent at an early stage.

- 6.5 There was a lack of feeding equipment available on the maternity wards, in some cases the special care baby unit was able to assist, in others there was a delay while suitable bottles were acquired from CLAPA. One family was so stressed over feeding, and unhappy at the lack of equipment on the ward, that they have purchased a stock and left them on the ward to prevent other parents going through the same experience. Some units only had one type of bottle so parents were unaware of the full range of bottles and teats available.

- 6.6 Many parents expressed gratitude to CLAPA members who visit them in hospital or at home to offer advice with feeding.
- 6.6 Even where there was equipment available, there was often a lack of knowledge or information regarding it's use, in one instance the only person who could assist was a doctor, while another parent was simply given a leaflet.

## 6.7 FEEDING SYSTEMS USED

	Cleft Lips	Lip and Palate	Cleft Palate
Normal bottle / special teats	11	7	4
Rosti	9	4	2
Chico	4	3	1
Haberman	5	11	4
Mead Johnson	2	2	1
Lambs teat / bottle	4	3	0
NUK	4	5	1
Squeezy / soft bottle	4	13	
Breast fed	5		

These figures represent more than 100% and are accounted for by parents reporting the use of more than one type

- 6.8 One parent commented on the fact that the question on the questionnaire assumed that a bottle would be used instead of breast feeding, while another felt there should be research into breast feeding and clefts.

## 7.0 THE HOSPITAL STAY

The table below refers to the age of the first operations only

	Lip	Palate
Immediately /within days	- 9	
1 mth	- 1	
2 mths	- 7	1
3 mths	- 39	2
4 -7 mths	- 16	28
9 -12 mths	- 2	29
1yr or more	- 0	12
Due or n.a	- 9	

## 7.1 SATISFACTION LEVELS WITH HOSPITAL STAY

### 7.2 [Q6b] *Were you satisfied with your stay in hospital ?*

Most parents approximately 80 % were satisfied with their stay in hospital, and few of these parents made any comments in this section. Of the satisfied parents three made comments such as, "the nurses were good, but the cleft team unavailable " or " the surgeon wonderful but nursing team poor. However the main sentiments expressed were " wonderful stay " " staff very helpful "

### 7.3 Dissatisfaction levels were concerned with staff attitudes, staff being abrupt or unhelpful, and babies not treated as individuals. Staff shortages also featured high, many parents felt they were expected to undertake the major caring and some of the nursing role.

*"I was expected to clean the wound....."*

*" Staff put too much responsibility on the parents....."*

*"...he would not stop crying, I was exhausted and needed to go home the nurse told me they were short of staff and he would be left to cry, he needed his mother "*



*"The procedure for the operation was never explained to us until he was admitted to hospital, we feel we would have liked to have known more at an earlier stage"*

*"There was too much conflicting advice about post operative care"*

7. 4 Two other main concerns related to the facilities, [ wards noisy, or poor facilities for parents who stayed overnight ] and staff not taking seriously parent's anxieties around post operative feeding, and their nervousness at taking their child home with a mouth full of packing. A small minority of these parents felt their child was discharged too early particularly if they had to return to the hospital daily which proved a tiring and time consuming experience. Some dissatisfaction was also tied up with the issue of pain control [see question 6b]

## 7. 5 CONTROLLING THE PAIN

7. 6 *[Q6b] After the operation did you have any concerns about pain control – if "yes" did the nurses put your mind at rest ?*

7. 7 45% of all parents had concerns regarding pain control, of these 18 % were reassured either by staff explanations or through their involvement with staff in determining the pain levels of their own child, and then working together to get the dosages and combination of medication right. For the remainder reassurance came as the medication worked.

7. 8 The remaining 27% [1-4 of all parents] continued to be concerned, the overwhelmingly reason being insufficient levels of medication, or what they considered to be ineffective medication. Many managed to work with staff to achieve a satisfactory level of pain control, others had to bully staff or demand additional medication, while some had to contend with staff attitudes that babies do not feel pain. In one case a baby had been given too high a dosage

- 7.9 A number of parents particularly mentioned pain as related to feeding. Parents accounts of the pain control experience were graphic and in some cases anguished, as reflected in the comments below.

*"The staff did not put my mind at ease, one nurse was abrupt and told me babies do not suffer from pain"*

*"The baby cried continuously I was frightened he was in pain and Calpol was given sparingly the nurses were very dismissive of me as an over anxious mum"*

*"When he had his palate repaired he was crying with pain for three hours all they would give him was Paracetamol until a change of shift"*

*"It was a struggle to get anything in the first place, and then they did explain everything"*

*There was too much pain, Calpol and Paracetamol were not enough, they said they used brandy but parents complained !"*

*"The pain was well controlled and they explained everything they were doing"*

*"They said he should not be feeling any sensation as it was not a painful operation, I do not believe that"*

## 8.0 THE CLEFT TEAM

- 8.1 [Q 7a] *Apart from the surgeon have you seen any other specialists from the Cleft team ?*

Speech and lang	- 86	Ear Nose Throat	- 64
Paediatric dentist	- 21	Orthodontist	- 53
Geneticist	- 20	Feeding adviser	- 23
Clinical Psych.	- 4	Paediatrician	- 41
Audiologist	- 9	Spec/ health visitor	- 4
Dietician	- 1	No contact	- 7

[ 1 stated no service necessary ]

A full breakdown of this table will be found in Annex 1.

8. 2 It is difficult to judge the significance of this information, it may be the severity of the condition, which would explain why children of similar age and condition were receiving very different services. It may be the availability of services within a Health District, or that children no longer require a particular service. The replies to the question relating to satisfaction levels were not very helpful as most were satisfied with the service they received and few made any specific comments.

### 8. 3 SATISFACTION LEVELS WITH THE CLEFT TEAM

8. 4 *[Q7b] Are you happy with the care you are receiving from your cleft team ?*

8. 5 Satisfaction levels were high, approximately nine out of ten were pleased with the care they received from their cleft team. Dissatisfaction stemmed from a number of reasons more related to quality rather than quantity although a few parents expressed concern at the lack of speech therapy provision, [one three year old had not seen a speech therapist for eighteen months and had no speech] The need for specialist speech therapists featured in many of the general comments, several parents pointing out that "ordinary" speech therapists were out of their depth when working with cleft children.

8. 6 One parent commented that they had to go out and seek all the services they needed, while another was concerned at the lack of funding for a specialist health visitor.

8. 7 Quality issues related to the lack of continuity; poor communication and cooperation between departments; cancelled appointments; being made to feel like a number instead of a individual; being shuffled to different departments to no avail; poor quality ENT services; misinformation to GP's. One parent was concerned that a new head of team disagreed and "rubbished previous treatment" which destroyed their confidence in the whole team, and lead to further surgery for their child. There were also delays in filling a vacant post

## 9.0 CONTACT WITH CLAPA

### 9.1 [Q8a] have you had regular contact with CLAPA ?

Yes - 77 No - 23 No reply 2

## 9.2 SATISFACTION WITH CLAPA

Satisfaction levels were extremely high, with only 3 parents indicating otherwise. There was much praise for the organisation. The service most appreciated by a ratio of 2 : 1 being the opportunity to meet other parents, to gain practical help and advice particularly with feeding difficulties, and the reassurance that comes from knowing other people who have had similar experiences. Many parents welcomed the opportunity to see children in more advanced stages of treatment looking so good, this was equally helpful for those children old enough to understand.

- 9.3 The News Letter and social gatherings were appreciated in equal measure, with the programme of talks providing valuable information, some parents regretted that the timing of the talks prevented their attendance.
- 9.4 Very few were dissatisfied with CLAPA's services, concerns related to not receiving information requested, one had sorted out their own problems before assistance arrived, another was denied practical assistance, one regretted that their branch was in-active.
- 9.5 One parent suggested that CLAPA should undertake fundraising in order to carry out research.

*"All my CLAPA team have been brilliant they are always there for me and my husband "*

*"I saw CLAPA when ..... was just a day old, in just a few minutes everything was turned around for me "*

*"Tremendous support from CLAPA"*

## 10.0 REFLECTIONS AND ADDITIONAL COMMENTS

- 10.1 The remaining two questions asked parents to reflect on how things might have been done differently and the service improved.
- 10.2 Not all parents chose to complete this section, but some had experiences to share while others wrote more detailed letters. Most of these comments have been incorporated into the main body of this report. The key issues parents would like action on have been used in the summary.
- 10.3 Below are some of the general comments

One parent advised against using oral syringes as her daughter had inhaled antibiotics in this way.

One parent was very interested in the theories linking folic acid supplements and the decreased incidence of clefts.

A parent felt that there were several large charities who were involved with clefts could get together to produce one book that had all the information that was available. A copy could be kept in all labour wards.

A parent would like a reading list.

One parent was concerned that parents might be put under pressure to have a termination when clefts were detected at scan.

One gave a good example of the value of training, a surgeon had commented that a cleft had only been detected as the Paediatricians had just had a talk about clefts, and been told to look carefully for them.





CLEFT PALATE TOTAL 25 [ 17 GIRLS 6 BOYS ]

GIRLS

Age in months	22	27	14	36	36	30	14	34	34	26	24	37	18	30	21	5	5
Speech/lang	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
ENT Surgeon	✓		✓	✓	✓	✓		✓	✓	✓	✓			✓	✓	N	
Paed. Dentist						✓	✓				✓					O	
Orthodontist	✓			✓	✓	✓		✓	✓	✓		✓					
Geneticist				✓		✓				✓	✓					S	
Feeding Ad.			✓		✓	✓										E	
Clinic Psych.						✓										R	
Paediatrician				✓		✓	✓		✓	✓						V	
Audiologist		✓	✓				✓									I	
health Visitor																C	
																E	
																S	

CLEFT PALATE CONT:

BOYS

Age in months	8	30	9	16	10	24	30	29									
Speech/lang	✓	✓			✓		✓	✓									
ENT Surgeon	✓	✓	N		✓	N		✓									
Paed. Dentist		✓	O		✓	O											
Orthodontist																	
Geneticist		✓	S			S											
Feeding Ad.			E	✓		E											
Clinic Psych.			R			R											
Paediatrician	✓	✓	V	✓		V											
Audiologist			I			I											
health Visitor			C			C											
Dietician			E		✓	E											
			S			S											

BILATERAL CLEFT LIP ONLY

TOTAL 3 ALL BOYS

NONE SPECIFIED LIP & PALATE

TOTAL 4 ALL BOYS

Age in months	18	9	36								12	32	11	8			
Speech/lang			✓								N	✓	✓	✓			
ENT Surgeon			✓								O	✓	✓				
Paed. Dentist			✓														
Orthodontist			✓								S	✓	✓	✓			
Geneticist											E						
Feeding Ad.	✓	✓									R						
Clinic Psych.											V						
Paediatrician											I	✓	✓	✓			
Audiologist											C						
health Visitor											E						
											S						



1a. Is your baby Male or Female? \_\_\_\_\_

1b. How old is your baby? \_\_\_\_\_

1c. What type of cleft did your baby have? \_\_\_\_\_

2a. Who first told you about your baby's condition? \_\_\_\_\_

2b. Were you happy with the way in which you were told? **YES / NO**

3a. How soon did you see the surgeon who would repair the cleft? \_\_\_\_\_

3b. Were you happy with the visit? **YES / NO**

4a. How soon did staff teach you to feed your baby? \_\_\_\_\_

4b. Were you happy with your baby's feeding? **YES / NO**

4c. Which feeding bottle was best for your baby? \_\_\_\_\_

5a. How soon did you visit the surgeon's clinic? \_\_\_\_\_

5b. Were you happy with the visit? **YES / NO**

6a. At what age did your baby have his/her first lip operation \_\_\_\_\_, palate operation \_\_\_\_\_?

6b. Were you satisfied with your stay in hospital? **YES / NO**

6c. Did staff make sure that your baby was not in any pain? **YES / NO**

7a. Apart from the surgeon have you seen any other specialists from the Cleft Team? (Please Tick)

Speech and Language Therapist.

Ear, Nose and Throat Surgeon.

Dentist.

Geneticist.

Feeding Advisor.

Clinical Psychologist.

Paediatrician.

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

Other. (Please specify) \_\_\_\_\_

7b. Are you happy with the care you are receiving from your Cleft Team?  
**YES / NO**

8a. Have you had contact with CLAPA? **YES / NO**

8b. Was this helpful? **YES / NO**