



CLAPA

Cleft Lip and Palate Association

Registered Charity No: 1108160

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Regionalisation of cleft lip and palate services: has it worked?

A report on users' perspectives of cleft care

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**Cleft Lip and Palate Association
www.clapa.com**

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1 INTRODUCTION

Eleven years ago, in 1996, The Cleft Lip & Palate Association was invited onto a committee set up by the Clinical Standards Advisory Group (CSAG) to review the treatment of cleft lip and palate at the time. In order to ensure that CLAPA's contribution to the committee accurately reflected the experiences and opinions of parents, a postal survey was undertaken.

The 1998 CSAG report on cleft lip and palate indicated that the state of cleft care was not acceptable in many areas; i.e. a number of children did not receive their surgery within an appropriate timeframe and an unacceptable number of children had significant difficulties with speech and feeding and many did not achieve a good outcome in terms of facial appearance after surgery (CSAG Report on Cleft Lip and Palate 1998).

Following the 1998 CSAG report cleft care in the UK was reorganised so that the expertise and resources were concentrated regionally taking into account population needs and accessibility. Over the next seven years the number of centres was reduced from 57 to 13 including a Scottish network of three centres. Each centre is required to provide services in accordance with strict protocols, set out in a Department of Health circular in 1998 (HSC 238).

In 2006, ten years later, CLAPA carried out a follow-up survey to study parents' experiences of their child's cleft care now that the majority of CSAG driven changes have been implemented. To ensure that the charity collected only the views of parents whose children have undergone treatment since the changes, we asked only parents of children three years of age or under to participate in the study.

This study was carried out to examine the current state of cleft care as experienced by parents and to identify areas where improvement has taken place and also to report any negative experiences. The results from this survey are discussed both in the light of the study done ten years ago and the CSAG recommendations.

2 METHODOLOGY

The 2006 questionnaire was posted out with the charity's annual newsletter, CLAPA News, in March 2006 and parents of children born with a cleft lip and/or palate three years of age or under were invited to take part in the study. Three hundred and seventy people who received the questionnaire with CLAPA News were identified to have been eligible to answer the survey. A further fifteen questionnaires were sent out to interested parents who replied to a notice on the CLAPA Parents' Smartgroup website. One hundred and sixty questionnaires were also distributed in the South Wales South West Cleft team area and thirteen questionnaires were sent out directly to CLAPA branch members.

A total of two hundred and twenty seven questionnaires were returned by parents of children born between 2002 and 2005, giving the survey a response rate of about 40%. This allows us to consider the experiences described by the respondents as an indication of the current state of cleft care as experienced by parents.

One hundred and two families completed and returned the 1996 questionnaire that was also sent to parents of children three years of age or under. In order to get more detailed information and to be able to examine the areas that were identified as problematic in the 1996 study, the original questionnaire was revised and new questions were introduced for the 2006 questionnaire. It is therefore impossible to make direct question to question comparisons between the two surveys though the questions covered many of the same areas.

The 2006 questionnaire was divided into seven sections with questions relating to the following: 1. Your child, 2. Diagnosis, 3. Treatment, 4. Feeding, 5. Surgery, 6. Cleft team 7. Other support. The questions were analysed separately and cross linkages were made only where it was possible to substantiate doing so. Parents were not asked to indicate where their child was being treated, so it has not been possible to compare the results between different areas and cleft teams.

The 2006 questionnaire also invited respondents to answer two open ended questions. One hundred and fourteen of the two hundred and twenty seven questionnaires contained written information relating to the following open-ended questions:

CLAPA is reviewing its services, is there something we could be doing that we are not?

Other comments – if there is anything else about your child's treatment or contact with CLAPA, please write comments here.

The written information was analysed to identify common themes, which were then coded, using the computer software package Atlas.ti. Once the coding had been completed, the data were examined for similarities and differences within themes, retaining the context of the written information from the questionnaire entries.

The quantitative analysis of the questionnaires was done by Sara Brookes and Dr. Andy Ness from the University of Bristol and the written information from the open-ended questions was analysed jointly by Dr. Gillian Woolhead from the University of Bristol and Kirsi Yli-Kaitala from CLAPA.

3 SUMMARY OF MAIN FINDINGS

The changes in cleft care over the last five years mean that the needs of families and children born with clefts are much better catered for than ever before. Ten years ago it was still largely other parents, under the umbrella of CLAPA, who guided and advised on some of the early care, especially around feeding. Nowadays the specialist cleft nurses provide that early care and tried and tested surgical protocols are in place meaning that babies receive surgery to a high standard, provided by a surgeon who has well-documented expertise and experience.

Results from the 2006 survey reflect these positive changes and show that most parents are mostly satisfied with care given by cleft teams. However, some of the issues parents were dissatisfied with at the time of the first survey still continue to raise concern such as lack of information and lack of staff knowledge and training in care of cleft children. The results from the 2006 survey draw particular attention to the following matters:

- Lack of knowledge of the condition both at the point of antenatal diagnosis and at the maternity wards; hospital staff was also unaware where to refer parents for feeding advice in 25% of cases.
- Delay in meeting a cleft team member after the diagnosis as only 48% of parents had seen a cleft team member within 48 hours after the diagnosis with 7% waiting up to six months*
- Delayed diagnoses, 14% of cases had been diagnosed more than 24 hours after birth.
- Intimidating and overpowering visits to the cleft clinic.
- Lack of information on how their child's looks would change after surgery.
- Not all the parents had been offered overnight accommodation when their child was in hospital for surgery which they should be entitled to.
- Pain control – concerns after surgery.
- Breastfeeding – only minority encouraged to try.

*individual cleft centre studies have shown much faster contact times – see page 10

The results from the survey will inform also CLAPA's work. The following points were raised:

- While a great majority of parents who had been in touch with CLAPA had found the contact useful and staff helpful there was evidence of the need to improve parents' awareness of CLAPA.
- Fewer than 50% of respondents knew if there was a local branch in their area.
- The scope of the services CLAPA offers was unclear for many respondents.
- The survey showed that trained CLAPA parent contacts are not used.

4 PROFILE OF THE SURVEY GROUP

The intention of the study was to survey children of three years of age or under and the majority of those who returned the questionnaires had children born in 2004 and 2005. Two questionnaires were returned for children that had not been treated in the UK and these were therefore removed from the study.

Table 1. The year the children were born

| | N (%) |
|------|--------------|
| 2002 | 27 (12.05) |
| 2003 | 47 (20.98) |
| 2004 | 71 (31.70) |
| 2005 | 79 (35.27) |

Table 2. Parents' description of cleft

| | N (%) |
|---------------------------------|--------------|
| Unilateral cleft lip only | 27 (11.95) |
| Bilateral cleft lip only | 4 (1.77) |
| Cleft of the soft palate | 48 (21.24) |
| Cleft of the soft & hard palate | 38 (16.81) |
| Unilateral cleft lip & palate | 78 (34.51) |
| Bilateral cleft lip & palate | 31 (13.72) |

5 FINDINGS

5.1 At the point of diagnosis

There has been a significant increase in the number of cases diagnosed antenatally; 45 % of parents who responded to the 2006 survey had an antenatal diagnosis compared with only 15% in the 1996 survey. It is surprising that in the 2006 survey as many as 14% of cases were not diagnosed at birth.

Table 3. The time of diagnosis.

| | N (%) |
|------------------|-------------|
| Antenatally | 103 (45.37) |
| At birth | 93 (40.97) |
| At a later stage | 31 (13.66) |
| within 24 hours | 10 |
| within 48 hours | 6 |
| within 1 week | 6 |
| within 1 month | 5 |
| within 3 months | 3 |
| within 12 months | 1 |

The amount of late diagnosis is worrying and calls for further investigation. Parents who had received late diagnosis expressed feelings of bitterness and resentment. In one case late diagnosis had resulted in dramatic weight loss of the baby due to problems with feeding:

“In relation to my daughter’s late diagnosis (12 days after birth) yes I still feel quite bitter that it was not picked up on, mainly because she lost over 15% of her birth weight and I was not able to breast feed..”

Parents who had received late diagnosis did not feel that they were listened to and felt pressurized, despite raising concerns about their baby's ability to feed.

"I did raise concerns about my daughter's inability to feed and that I thought there was a problem, but it took 12 days until I was listened to."

"We were distressed that diagnosis took so long even though we had feeding difficulties and concern was expressed by GP, health visitors and paediatrician about her lack of weight gain in early weeks. Pressure was put on us to get her to feed better even though we now know she had a physical reason for not feeding well. Her symptoms and problems have since been described as a 'classic feeding history of cleft palate'."

The incidence of late diagnosis does not appear to have reduced in the last 10 years. Given the extreme distress that can result from this CLAPA believes that more training should be given to those that conduct post-birth checks to identify what in most cases is an obvious condition to diagnose.

5.1.1 Receiving the news

In 1996 one in three parents was unhappy with the way they were told about their child's cleft. The results from the 2006 survey show that a number of parents are still dissatisfied with the amount and quality of the information and the support they receive at the point of diagnosis:

- 32% of parents felt that the person delivering the news wasn't knowledgeable about the condition at the point of diagnosis.
- 26% of parents didn't get all the information about the condition they felt they needed to know at that time.
- One in five parents also felt that they hadn't had enough support from the health professionals at the point of diagnosis.

The answers to the open-ended questions gave further information on parents' experiences at the point of diagnosis; some parents felt that 'breaking the news' at the 20-week scan was an area that should be improved and others who had received the diagnosis at birth felt that the information was badly presented.

"My antenatal diagnosis experience was not very good. The hospital had no leaflets or information to give me – other than a reassurance that someone would contact me from the cleft team. I had to find info myself via the web. I tried my local health visitors who surprisingly didn't have any experience of clefts and gave me an out of date CLAPA number."

"I am sure you have moved things on in terms of training for sonographers at antenatal diagnosis. 'Breaking the news' could have been much improved."

"The news about my daughter's palate was not told to us in the best way and left us upset and confused."

“Initial questioning in hospital – less than 24 hours after birth, regarding possible causes of cleft was insensitive and shocking - and seemed to look to appoint blame, i.e. I was asked a question about inbreeding?!”

Parental satisfaction and dissatisfaction at the point of diagnosis centred on the quality and amount of information, staff attitudes and behaviour, the level of support available and the professional knowledge and understanding of the condition. The accuracy of the diagnosis was also important as described by one respondent:

“My son was diagnosed at the 22 week scan with cleft lip, palate and gum yet when he was born it became apparent that he only had a cleft lip. The referral letter stated he had 'facial abnormalities' and a gap of 4mm which I found very distressing. How could they get it so wrong? I almost wish I hadn't known, as the diagnosis was so much worse than reality.”

5.1.2 Care provided by maternity wards and local health services

One of the most recurring themes in parents' answers to the open ended questions was the lack of knowledge of cleft lip and palate in maternity wards and local health services. Many parents raised concerns regarding their child's care at the hospital during the first days after birth as they felt that the hospital staff were lacking information and knowledge about the condition.

“No staff familiar with cleft lip/palate. If it wasn't for the cleft palate team we'd know nothing. When our son was born, no one at the hospital knew anything about cleft palate.”

“Perhaps maternity units and local health visitors could be better informed – mine were completely useless.”

“My local hospital, where I had my scan and then my baby, were not fully informed or completely helpful.”

“The hospital in which I gave birth didn't have much knowledge or experience of clefts on any level and on several occasions have offered no or conflicting advice.”

“My first daughter was born in 2000. In 2004 my 2nd daughter, also with cleft, was born – our local hospital was still no better informed. Hospitals and midwives need more information, equipment and support. As do the parents immediately after birth, especially when the cleft is unexpected. I have a cleft, as do 2 of my daughters – it was still a more difficult time than it should have been.”

“Hospitals need to be helped with setting up their protocol of when cleft children are born. Need to explain health visitors how to deal with clefts with understanding and care.. If mine refers to it as 'issues' one more time I might scream.”

5.2 EARLY TREATMENT

5.2.1 First meeting with the cleft team member

The fact that there remains a serious lack of knowledge about cleft lip and palate at maternity wards and in local health services makes the role of the cleft team in delivering accurate information and giving support at the early stages after diagnosis all the more important. However, the 2006 survey revealed that only 48% of parents had seen a cleft team member within 48 hours after diagnosis and 7% had to wait between one to six months before seeing a member of the cleft team.

Table 4. How long after the diagnosis did you see a member of a cleft team

| | N (%) |
|------------------------------------|------------|
| Within 24 hours | 60 (27.15) |
| Within 48 hours | 47 (21.27) |
| Within 1 week | 38 (17.19) |
| Within 1 month | 47 (21.27) |
| Within 6 months | 16 (7.24) |
| Within 2 months of antenatal diag. | 12 (5.43) |
| Can't remember seeing anyone | 1 (0.45) |

We were surprised at the delay in meeting a cleft team member and wondered whether parents might not consider a cleft nurse as part of the team. However the question was clear and stipulates “for example, a cleft nurse”. The open ended questions also give a good indication that parents were generally well aware of who the cleft team were and when their support stepped in. As the parents were not asked to indicate where their child was being treated it is not possible to compare the results between areas apart from the South west cleft team area where questionnaires were sent out with a different design. Further analysis shows that there is no significant difference between responses from South West and the remaining areas, although it still remains possible that there are regional differences. For example we have seen some studies indicating that new parents are met by a member of a cleft team well within the recommended 48 hours. For instance the South Thames Cleft Service birth audit for the year ending March 2006 shows that of 112 births, 91% of babies were referred within 24 hours of diagnosis and 95% seen by a cleft nurse specialist within 24 hours of referral. These outcomes are reflected in other cleft centres where there is a well-resourced nurse specialist team.

The CLAPA survey shows that parents are mostly very pleased with the first meeting with the team member and found the information they received at that time helpful (86% of parents). A great majority (76%) of them also felt that their concerns about their child's treatment or condition were very well addressed.

“ At my son's birth his treatment was pretty appalling – no one seemed to know anything about clefts. However, once the nurse specialist arrived she took control and told us everything we needed to know.”

“My local hospital, where I had my scan and then my baby, were not fully informed. But once the cleft team became involved the care and support has been fantastic.”

“Although the cleft team sent information out quickly, no information was offered by our maternity unit.”

5.3 FEEDING

5.3.1 Establishing feeding

Nearly 70% of all mothers achieved successful feeding patterns within the first day after the baby was born. However, the 2006 survey showed that the hospital staff didn't know where they should refer parents for feeding advice in nearly one in four cases. This, along with the delays in seeing a cleft team member after the diagnosis suggests that the referral system is not working as smoothly as it should. This is worrying in terms of establishing successful feeding as the survey revealed that specialised feeding bottles were not available on 70 % of maternity wards.

Fifteen parents reflected the lack of information on feeding from nursing/midwife staff and the inadequate supply of feeding equipment on the hospital wards in their answers to the open-ended questions:

“More information and feeding equipment available to midwives and mothers on postnatal wards”.

“When our son was born, no one at the hospital knew anything about cleft palate. The best advice we got on feeding was to squeeze the teat.”

“My NHS local health professionals were utterly useless – I completely relied on the cleft team and CLAPA for support and advice – especially with early feeding issues.”

“ALL hospitals could know who to contact for feeding support.”

“Ensure that all maternity hospitals carry supply of soft bottles and several staff trained to use them.”

If a successful feeding pattern was not established within a short amount of time this caused considerable anxiety for parents especially as this often meant that the baby lost

weight while another method was tried. In once case lack of information on feeding had serious consequences:

“Hospital staff were not very well trained in feeding cleft babies and so it wasn’t until my son went yellow with jaundice that he got the special attention required in the special baby unit. If they were able to feed my son effectively then he would not have ended up going yellow. Meant we had to stay in hospital longer. Were not told that our sons nose could get blocked with milk and that babies cannot breathe through their mouths. He ended up in emergency and we thought he was going to die.”

5.3.2 Perceived support when establishing feeding

Although a majority of parents felt supported in establishing feeding, 11% felt that they weren’t supported at all during this time. This too was reflected on parents’ written comments:

“It may not be your role but I found midwives and health visitors lacked any knowledge about feeding and caring for cleft babies. My specialist nurse was too far away to visit and I felt unsupported at first – left to discover things myself and baby a novelty.”

“The hospital in which my child was born was useless and lacked knowledge and information. They wanted to refer him to the intensive care unit for feeding for a uni cleft lip only and there was not any specialised teats/bottles for feeding. Made my first few hours with my baby a disappointment – total utter nightmare.”

5.3.3 Breastfeeding

Babies with cleft lip only can usually breastfeed but breastfeeding is more difficult if the baby is born with a cleft palate due to the difficulty in creating a vacuum. When asked about breastfeeding, we found that 55% of mothers weren’t encouraged to try to breastfeed their child at all and parents were concerned that there was a lack of advice on breast feeding. This resulted in some mothers who would have liked to try to breastfeed being discouraged while others were pressured into breastfeeding when it clearly was not going to be successful.

“I just wish hospital staff were aware of the condition, but I know this is demanding due to many medical conditions. I was distressed feeding my baby without soft bottles and endlessly encouraged to breast feed when couldn’t (up to the first day of giving birth).”

Determination on the behalf of some mothers themselves helped them to persevere with the difficulties of breastfeeding:

“There was no help or encouragement for me expressing long term. I had to buy a decent pump (£175) because the hospital needed theirs. I persevered through disdain from dieticians that I was still expressing at 8 months.”

“However I do think I only managed to successfully breastfeed because I was determined to do it, having done it before – maybe some more support there would have been helpful.”

Many parents expressed gratitude to CLAPA for offering information on feeding and commented on the speed of service when ordering feeding equipment.

5.4. SURGERY

5.4.1 The quality of information given before surgery

The children in the 2006 survey underwent their first lip operation at the average age of 3.5 months; the first palate operation was done when the children were approximately 8.3 months old. A great majority, nearly one in nine parents, were very satisfied both with the amount and quality of information given by the surgeon before their child’s first operation. Three comments to the open-ended questions also explicitly stated that they were very impressed with the pre and post operation care:

“Overall I have been very impressed with the before and after surgery treatment by the cleft team.”

While most parents were very satisfied with the information given before surgery, 5% felt they hadn’t received enough information on the important issue of how their child’s looks would change after the operation.

“As a mother I found it very hard to bond with my baby as he looked so different and changed so much in personality.”

One parent also stated that the information given regarding the operation was too simplistic and as a result did not fully prepare the parents for the outcome:

“The information we received about the operation, recovery and pain was very ‘watered down’ and as a consequence we believed it was less serious than it was in reality. Although this may make parental life easier pre-operation, it made post-operation much more stressful as we were unprepared for the trauma our baby and we would suffer.”

5.4.2 Concerns regarding surgery

While parents were generally content with the meeting with the surgeon before the operation and the information they were given, some – mostly isolated – concerns were raised. One parent at the pre-operation stage was concerned that they only saw the consultant once and that they had to wait for confirmation of surgery:

“Prior to the operation we only met the surgeon once before at an initial clinic appt. No other contact has been made. Had to chase the team for surgery date

and letter of confirmation only came through approx 3 weeks prior to surgery – not helpful when arranging time off work/nursery placement etc.”

One parent also felt upset by the lack of compassion shown by the staff with regard to the prospect of putting a baby through surgery:

“As parents we initially felt quite upset at the lack of compassion for parents at the hospital as it is very distressing to put your 3 month old baby through surgery.”

A further two parents would have liked to have had more information about after-care and painkillers:

“More help and advice post operatively. We felt very alone after our child's first operation.”

Four parents requested that there be more check-ups after the operation of the cleft lip/palate.

“ Now that my son has had his two operations – I feel there has been no contact since!!! Apart from yearly check-ups. A phone call say every 6 weeks would be lovely.”

5.4.3 Pain control and overnight stay in the hospital

In the 1996 survey as many as one in two parents had concerns regarding pain control and though there has been considerable improvement on this area, 7% of parents were still worried about their child being in pain. However there was only one written comment regarding pain control.

While a great majority of parents had been offered overnight accommodation when their child was in hospital for surgery, this option was not available for eight respondents.

5.5 CLEFT TEAM

Parents' satisfaction levels with care provided by the cleft team were very high in the 2006 survey as expressed by the following:

- 81% of parents were completely confident with the care they were receiving from their cleft team, 16% were to an extent and only 2% were not satisfied.
- 90% of parents who had worries or fears felt they were completely or to an extent addressed by a member of the cleft team, only two respondents felt that their worries weren't addressed at all.

- 70% rated the care their child was receiving from the cleft team as excellent, 24% very good, 5% good and only 1% fair.

Parents' comments to the open-ended questions further discussed satisfaction levels with the cleft team and 39 comments described the team as helpful and supportive.

"We were really pleased with the care our son has received from the team. We have felt looked after since day one."

"We are overwhelmed at the help and support available from CLAPA and the cleft team and feel our daughter is exceptionally lucky to have so many people interested in her welfare."

"Cleft nurses are essential in my view, as they allow time and care for each specific child and family and are a great source of information, support and are available to help wherever and whenever they can. They were invaluable to us."

Suggestions for improvement within the cleft teams were highlighted by a minority of parents and included providing more booklets and more "before and after" surgery photographs; parents also expressed a wish for the cleft team to be more realistic with the outcome of the child's surgery and to provide a more holistic service.

5.5.1 Members of the cleft team

One of the key recommendations of the CSAG report was that care should be multidisciplinary. When asked which of the cleft team members families had met so far, the 2006 survey revealed that:

- Over 90% of parents had met with a surgeon, a cleft nurse and a speech and language therapist; many had also already met with
a dentist (50% of parents),
an orthodontist (48%)
a paediatrician (42%)
a geneticist (33%)
a clinical psychologist (24%)
and a paediatric dentist (18%)

The results from this are encouraging as apart from the surgeon and cleft nurse many of the parents had already met with other team members including a clinical psychologist. This suggests that CSAG recommendations regarding the multidisciplinary make up of teams seem to have been implemented fully.

5.5.2 Joint Clinic

A majority of the cleft clinics are now joint which means that when parents attend the clinic the whole team is present. 81% of respondents indicated they attended joint clinics

and most these expressed appreciation at the opportunity to talk to the whole team about their child's treatment. However, there were 44 written comments regarding joint clinics, most of them describing the situation as intimidating, overwhelming or daunting.

"I find it quite overpowering because its usually just the surgeon who talks and the rest just take notes and watch - it feels like an interview."

"Parents need to be warned as it is very intimidating at first."

"They never introduce themselves, they just sit and look at us. We feel like guinea pigs."

"Sometimes it was quite daunting, new baby and big medical team can be quite an intimidating combination."

The number of written comments that described the joint clinic situation in negative terms raises a question whether the clinics can be modified to address these concerns.

A few parents however commented that it was useful to have so much information at once:

"It helps to make notes to make sure all of my concerns are covered."

"It's good to have them all available but is sometimes a bit off putting talking to so many people."

"Like the fact that you see hearing and speech specialists together. "

5.5.3 Distance to travel for appointments

The distance parents would have to travel for surgery if care was regionalised was an important part of the CSAG debate. The CSAG report concluded that parents would be expected to travel further for surgery but should be able to continue with routine appointments nearer home. The results from the 2006 survey show that the average distance parents have to travel for surgery is 44 miles and for routine check-ups 23 miles. This indicates that the CSAG recommendations are working. No respondents commented about time and length of journeys.

5.6. OTHER SUPPORT AND CLAPA

About half of the parents who responded to the 2006 survey had been, or still were in contact with other parents of children with clefts. It was, however, left somewhat unclear as to how they had met. 19% of parents were introduced to other parents by the clinical nurse specialist but a majority reported that they were introduced by someone else; mainly friends or people who they met at hospital or through websites. It was also left unclear as to whether these contacts were members of local CLAPA branches.

Parents' answers to the questions regarding CLAPA and its work revealed that the organisation needs to become more visible and accessible. Fewer than 50% of parents knew if there was a local CLAPA branch in their area and many parents were unaware of the scope of services that CLAPA provides. However, 85% of the parents who had been in touch with CLAPA had found the contact useful and 93% had found the individuals helpful with 90% getting the information they needed.

Parents' comments to the open-ended question relating to CLAPA's services were mostly positive with 18 parents describing the organisation as excellent, due to its provision of support, advice and equipment for families.

"We think that CLAPA is a very important association and it should continue to support the families and cleft specialists as much as possible."

"I think you do an excellent job and the service has been invaluable to us. Thank you."

Parents specifically found the magazine supportive and interesting and a further six found the parents' forums and website useful:

"We eventually contacted CLAPA parent's board for advice to help him through. I would like to add that the new CLAPA forum is absolutely fantastic and I have recommended it to several people."

However, one parent wanted more photographs on the website to show what a cleft lip/palate looked like, another wished the website was more detailed, and a further parent thought the literature should be regularly updated on the website. One parent saw the CLAPA logo as a negative image and required updating.

The comments to the open-ended questions further revealed that there is a need to improve awareness of CLAPA and its services and to raise the profile of the organisation.

"More information on your services."

"Awareness is essential – push for public awareness, talks in schools etc."

"Making the awareness of CLAPA available at doctor's surgeries because six people have had babies with cleft lips and palates in our town and information has been scarce. Would be useful if there was an actual CLAPA branch in area."

We would like to know more about CLAPA in our area and we would like to meet other families. We would like to be more involved in CLAPA, perhaps receive more information on events that are happening in our local area."

The survey further revealed that CLAPA's trained Parent Contacts are not used efficiently as less than 10% of parents had been in touch with a CLAPA parent. However many parents expressed a wish to meet other parents so there clearly is a need for the service and it needs to be better promoted.

It became clear from the comments to the open-ended questions that some parents still do not distinguish between CLAPA and the cleft teams, i.e. a cleft nurse was understood to represent CLAPA in a few comments. This again calls for raising awareness of CLAPA.

6 DISCUSSION

Cleft care in the UK in 2006 is a world apart from what it was in 1996. The comprehensive review of cleft care undertaken between 1995 and 1998 by the Clinical Standards Advisory Group highlighted significant weaknesses which, in the years since 1998, the Department of Health has attempted to address through a complete re-organisation of cleft care. Has it worked?

There have been many voices over the last ten years calling for ways of measuring the effectiveness of the changes through audit, inter-centre reviews, patient satisfaction surveys and monitoring of outcomes within specific disciplines. In an ideal world it would have been useful to have undertaken a complete CSAG-type review all over again. There have indeed been numerous local and regional studies undertaken by a variety of bodies and disciplines. However, no one has attempted to undertake a national snapshot of experiences. This study, like the one conducted by CLAPA in 1996, is an attempt to get a flavour of where things stand from users' and patients' perspectives. Of course, it has its limitations: respondents are self selecting, they are all in some way involved with a support group (CLAPA) and we cannot know that respondents are equally distributed throughout the UK. Yet the number of returned surveys was high (200 - nearly 50% return rate of those eligible) and the quality of responses generally good. However one measures how representative a survey might be of any population, there is no denying that this survey provides a comprehensive list of things that, in 2006, are of concern to families with babies born with cleft lip and palate.

The good news is, that in 2006, the concerns expressed by parents are generally not around cleft care. Four out of five parents were completely confident with their cleft team and nine out of ten felt all their information needs were being addressed. There were some areas that could be improved, but these were not around the actual care received, rather the nature of some clinic appointments (not user-friendly) and in some instances professionals being over-reassuring about surgery, without painting the full picture. The CSAG recommendations highlighting the importance of a truly multidisciplinary approach to care have been implemented fully with, in most cases, parents having access to all the key core team members and disciplines. Travel to and from in-patient surgery, or to and from routine appointments at the regional centre, was not flagged up by a single respondent as being of concern. Again, the CSAG commitment to ensure routine appointments continue nearer home seems to be working.

But while cleft care has certainly been seen to improve over the last decade, most of the concerns expressed in 1996 around diagnosis and maternity care, and the care provided by non-cleft "front line" health professionals seem still to be apparent. More than one in ten clefts is not diagnosed at birth. Ante natal diagnosis has increased but there are still horror stories around "breaking the news" and lack of information. Respondents to this survey indicate that in some cases there is an unacceptable lapse in the time between diagnosis and the first visit of a cleft team member especially ante natally; this may

largely be the result in a breakdown in referral mechanisms. There must be immediate improvements in referral times and hospital staff must be made more aware of how to diagnose a cleft post birth and to whom they should refer. An overview of cleft lip and palate should be given to all trainee midwives and sonographers. The respective training bodies should be instructed to implement this. It is the job of the cleft teams, too, to ensure that all units in their referring region have up to date information on how to make referrals. The teams, and CLAPA, should work together in ensuring that all “front line” health professionals are better informed about cleft lip and palate.

Most survey respondents are happy with the service they have received from CLAPA. However, it is clear that CLAPA needs to improve information on the services it provides as many people are not aware of what they may have gained through contacting CLAPA. Parent Contacts are little known about and thus infrequently used. This, too, is the responsibility of cleft teams in terms of promoting CLAPA but the organisation needs to make it easier for teams to do this by providing more literature and promotional material. Many cite the website as a very useful resource but this needs continual updating to maintain its relevance. CLAPA’s feeding service continues to be its key visible and effective service and perhaps more could be done to promote the general work of the charity through this specific service.

7 RECOMMENDATIONS

Based on this study CLAPA makes the following recommendations:

- i) Enquiry into how to best inform and keep updated “front line” health care professionals at the point of diagnosis
- ii) Enquiry into delayed diagnosis
- iii) Changes to joint team clinic approach – emphasis on “user-friendly” clinics
- iv) Target time of 48 hours for first visit by member of cleft team after diagnosis must be achieved UK-wide.
- v) Better information on patients’ appearance post surgery – what to expect
- vi) 100% availability of hospital overnight accommodation for at least one parent/guardian
- vii) More reassurance about pain relief
- viii) CLAPA to be more visible and accessible
 - i) Better website
 - ii) More posters at clinics
 - iii) Better referrals by health professionals to CLAPA – trained Parent Contacts are currently not used
 - iv) Better promotion beyond the cleft teams (GP’s, health centres etc.)
 - v) Circulation of newsletter to health professionals on regular basis explaining our work.

8 REFERENCES

Clinical Standards Advisory Group: Report on Cleft Lip and Palate, 1998

HSC Health Service Circular 1998/238.

Appendix I

Response from Cleft Development Group

This is an excellent piece of work and reflects enormous credit on CLAPA.

The Cleft Development Group (CDG) is very pleased to see the positive references to both the Cleft Teams and to CLAPA itself. It is encouraging that there has been so much improvement since the re-organisation of cleft services in the UK but the report clearly shows that there is no room for complacency.

Missed and late diagnosis is a major concern. Ignorance of clefts and the needs of cleft babies and their parents in maternity units is a real problem and is shared with most other congenital abnormalities. There needs to be some central action to address this. The CDG will be joining with CLAPA in putting pressure on the Department of Health to raise awareness of correct procedures following the birth of a baby with a cleft.

As well as bringing this to the attention of the Department of Health, we also need to target obstetricians, midwives and paediatricians. Because those staff may only see a cleft baby very rarely, it is necessary to renew contacts with them on a regular basis and ensure that they are well provided with literature. We acknowledge CLAPA's efforts in this respect.

Of concern to the cleft teams is the lack of knowledge which clearly exists in some areas of whom to contact when a cleft birth occurs. This and the time interval to the first contact with the cleft team need to be addressed.

We were reassured by the absence of complaints about the distance families need to travel for operations as this had been a potential concern during the re-organisation of cleft services. As envisaged it seems the majority of patients are able to attend routine, ongoing appointments nearer home. This is something that needs to be monitored and all centres must continue to ensure as much non-surgical care as possible is available near the patient's home.

Nigel Thomas, Chairman, Cleft Development Group 2004-7
Adrian Sugar, Chairman, Cleft Development Group 2007

March 2007

Appendix II

Response from Craniofacial Society of Great Britain and Ireland

This report describes a significant piece of work and is undoubtedly the most important document relating to services for young people with cleft lip and/or palate since the original CSAG recommendations were published.

The Society will shortly be holding its 2007 Conference and Council have agreed that it should be reviewed by each of the specialty groups during their pre-conference meetings. Time will also be set aside during the Annual General Meeting for a preliminary discussion on how the Society and the Teams around the country can best address the important issues raised by the report, in particular the need for better initial responses and support at the time of diagnosis in the general maternity services.

The CSAG report set us off on a journey that families and service providers must take together. Speaking on behalf of the Craniofacial Society as a whole, I can assure you that this is a partnership to which we are fully committed.

Bill Shaw
President Elect
Craniofacial Society of Great Britain and Ireland

March 2007