CLAPA Regional Coordinators Project

Evaluation Report

March 2012

Report contributors:

Miss Nicola M. Stock (Research Associate, Centre for Appearance Research)

Ms Claire Cunniffe (National Coordinator, Cleft Lip and Palate Association)

Dr Elizabeth Jenkinson (Research Fellow, Centre for Appearance Research)

Professor Nichola Rumsey (Co-Director, Centre for Appearance Research)

This report was produced by the Centre for Appearance Research, University of the West of England, Bristol, on behalf of the Cleft Lip and Palate Association.

Acknowledgements
With many thanks to:
All staff at CLAPA for their continued support, and for being a pleasure to work with.
All staff at the Centre for Appearance Research for ongoing advice and encouragement.
All those who contributed to the Regional Coordinators Project evaluation, including focus group participants, respondents of the online survey, testimonial providers and so on.

NB: Claire Cunniffe has now been appointed as the CLAPA National Coordinator.

Report Contents

CLAPA Regional Coordinators Project – Evaluation Report
Executive summary

Cleft lip and/or palate (CL±P) is the most common congenital craniofacial condition, affecting approximately 1 in 700 live births per year in the UK. The cleft and its treatment pose a number of challenges for those affected and their families, and having access to appropriate support when it is needed is a vital factor in psychosocial adjustment. The implementation of localised support is a frequently requested and highly valued service, with proven potential to have a positive impact. In 2010, the Cleft Lip and Palate Association (CLAPA) obtained funding from the Vocational Training Charitable Trust (VTCT) to employ a full-time Regional Coordinator to pilot local services in the East of England for one year.

The main aims of the pilot project were as follows:

1. To increase branch and volunteer capacity
2. To provide face-to-face support for parents
3. To support children and young people to build social networks
4. To provide support for adults with a cleft
5. To raise awareness of CL±P amongst the general public
6. To provide training and support for non-cleft specialist Healthcare Professionals (HCPs)
7. To promote and support user involvement

The Centre for Appearance Research (University of the West of England, Bristol) conducted an evaluation of the project, utilising both quantitative and qualitative methods of data collection and analysis.

The **findings of the evaluation** can be summarised as follows:

- The amount and range of volunteering activity in the region was significantly increased and diversified. Volunteers felt empowered to provide information, advice and support to others.
- Links with hard-to-reach communities, local schools, NHS cleft teams and a variety of different charities and organisations were formed and enhanced.
- Local parents, children, young people and adults affected by CL±P have benefitted from a wide variety of social, fundraising and awareness-raising events and groups.
- Ongoing user involvement has guided the project and been central to the evaluation itself.

A number of **key areas for development** were identified:

- The development, evaluation and implementation of standardised, formal training for non-cleft specialist Healthcare Professionals in relation to diagnosis and treatment of CL±P was identified as a priority for future work.
- A basic level of counselling/listening skills training for all staff engaging with vulnerable groups is highly recommended.
- Ongoing development of existing regional resources in the East of England is encouraged, as is the gradual expansion of these services throughout the region and across the UK.

Introduction

Background and project rationale

A cleft in the lip and/or palate (CL±P) is the most common congenital craniofacial condition, affecting approximately one in 700 live births per year in the UK. For most parents, the 'diagnostic event' is an emotionally demanding experience, and families often express a number of concerns. Complex multidisciplinary care continues throughout the child's lifespan, forming an underlying and unremitting stressor in the family's lives. The cleft and its treatment can also pose challenges for the affected individual in many domains of life, including several areas of psychological and social functioning. Although the majority of individuals and their families adjust well, many need additional practical and emotional support. For others, the cleft is a cause of significant distress. Access to appropriate and professional support is therefore vital to encourage positive psychosocial adjustment and ultimately improve outcomes.

The Cleft Lip and Palate Association (CLAPA) is the only national charity dedicated to supporting all people with and affected by CL±P in the UK. They represent the voice of patients, parents and a multitude of healthcare professionals (HCPs) working in the field of cleft. CLAPA's overall aim is to further improve the quality of life of all those affected by CL±P by providing effective services in all sectors of the community.

CLAPA is already well-established throughout the UK, providing a number of highly-valued national services. As part of their recent strategic review, CLAPA conducted a National Survey open to anyone interested in CL±P ('CLAPA 2010 Survey'). A key finding of this survey was the clear need for more support at a local level. Although local support is already provided by CLAPA's network of local branches, significant gaps and limitations in this service has been observed. In addition, the amount of branches across the UK is decreasing, due to insufficient numbers of volunteers. As a result, some regions only have one branch, and other regions are no longer provided for. In a previous one-year project, CLAPA employed a Network Assistant for one day per week to develop local services within the East of England. Although this project was a success, one day per week was not considered to be sufficient to effectively deliver the activities required. In 2010, CLAPA obtained funding from the Vocational Training Charitable Trust (VTCT) to pilot a full-time Regional Coordinator (RC) in the East of England for one year (Claire Cunniffe).

The main aims of the RC pilot project were as follows:

1. To increase branch and volunteer capacity
2. To provide face-to-face support for parents
3. To support children and young people to build social networks
4. To provide support for adults with a cleft
5. To raise awareness of CL±P amongst the general public
6. To provide training and support for non-cleft specialist HCPs
7. To promote and support user involvement

The Centre for Appearance Research (CAR) based at the University of the West of England in Bristol was asked to evaluate the effectiveness of the CLAPA RC pilot project. If the pilot was considered to be a success, CLAPA hoped to obtain further funding to extend the project to other regions across the UK.

This report

This report describes the findings obtained from the evaluation thus far. Supplementary data may be included at a later date.

Across the UK, CLAPA's branches are run primarily by volunteers. In the East of England region, CLAPA currently have only one branch, referred to as the Cambridge Branch. Also in Cambridge is Addenbrooke's Hospital, the main site for multidisciplinary cleft care in the East of England. This network is referred to as Cleft.Net.East. A glossary of key terms is provided in the appendices.

Evidence

Evidence for this evaluation has been drawn from various sources, including a focus group with parents of children born with a cleft, results from an online survey with parents, individuals with a cleft themselves and HCPs, a selection of case studies and testimonials written by those who have been affected by the project, and other formal documents collected by both CLAPA and CAR throughout the pilot year.

The hour-long focus group was led by CAR in May 2011 and aimed to establish unmet local need. Discussion centred on the sources of support that parents currently access for cleft-related issues, and what type of local services they would like to see improved or implemented. Inductive thematic analysis revealed a number of key messages and several recommendations were made. More information can be found in section 7, and an executive summary of the focus group study is provided within the appendices of this report.

The online survey, designed and managed by CAR, collected quantitative and qualitative feedback from 40 parents of children affected by CL±P, 9 individuals with a CL±P (young people (YPs) aged 16 years and above, and adults) and 11 HCPs working in the field of CL±P. Results from the online survey are included throughout this report where appropriate.

Structure

This evaluation will address each of the pilot project aims in turn, beginning with a brief overview of the rationale behind each aim. The evidence for each of these rationales has been primarily derived from work previously conducted by CLAPA. This is followed by a description and an evaluation of the RC's efforts towards each aim over the pilot year. Supplementary documentation, including information about methods and analyses, is provided within the appendices of this report.

1. Increasing branch and volunteer capacity

CLAPA has a strong tradition of volunteering. However, they have found it increasingly difficult to recruit and retain volunteers, resulting in inequitable local provision. Previous work has demonstrated that volunteers are keen to be involved, but require more support, improved facilitation and communication, and the ability to provide more consistent messages. In addition, although the incidence of CL±P is similar across all ethnicities, Black and Minority Ethnic (BME) communities are currently underrepresented within CLAPA's membership and activities. Finally, the various CLAPA branches are keen for opportunities to increase their services and to enhance links with various internal and external groups.

1.1. Recruiting and training volunteers

The East of England is currently covered by only one branch, based in Cambridge. Before the pilot project began, the Cambridge branch consisted of only a handful of Branch Committee members, and was not actively recruiting more volunteers. In order to further develop and support the branch, the RC has worked with colleagues at CLAPA to create a procedure for recruiting and training volunteers. This included the design of a Volunteer Induction Programme for potential volunteers. The Induction Programme was trialled in May 2011 and subsequently held on two other occasions due to the amount of positive feedback received. A list of these training events is displayed below in Table 1. Individuals are still able to volunteer informally if they wish to, but more active participation now requires standardised formal training, references and a CRB check.

Table 1: Training events held for new and existing volunteers

Event	Date held	Location	Target group	Organiser
Volunteer Induction Training	May 2011	London	Potential / existing volunteers	CLAPA / the RC
Volunteer Induction Training	June 2011	Corby	Potential / existing volunteers	The RC
Volunteer Induction Training	October 2011	Peterborough	Potential / existing volunteers	The RC
Parent Contacts Training	October 2011	Corby	Potential volunteers	The RC / CLAPA
Parent Contacts Refresher Training	November 2011	London	Existing volunteers	The RC / CLAPA

Volunteers are currently being recruited via the main CLAPA website, the branch website, social networking websites and CLAPA newsletters. Table 2 below illustrates the level of interest in volunteering, the number of people who completed formal training and the number of active volunteers during the pilot year. The initiation of this programme sparked interest across other regions of the UK, as also demonstrated below. Volunteer Induction Training will now be offered every quarter, while Parent Contacts Training will be offered twice per year.

Table 2: Statistics illustrating the activity of official volunteers during the pilot year.

Official Volunteers (including new Parent Contacts)			
	No. of people who completed application forms	No. of people who completed formal training	No. of people actively volunteering (31.01.2012)
East of England	22	17	16
UK	89	32	29

Following their training, volunteers have gone on to participate in a number of activities. All of these volunteers have been retained.

As part of the online survey, participants were asked about their experiences of volunteering for CLAPA. Those who had volunteered in the last year were highly active, participating in a wide range of activities, including fundraising, local branch activities, awareness raising, social activities, running support groups, providing ongoing support to others as a parent contact and volunteering at NHS cleft clinics. Many of those who had not volunteered for CLAPA before were interested in volunteering in the future, having been made aware of the opportunities available to them through the RC. All those who had completed formal volunteer training rated this training as either 'good' or 'very good'. Participants were also given space to comment on their volunteering activities if they wished to. A selection of these comments is provided below illustrating the role of the RC in motivating, supporting and retaining volunteers to increase branch capacity.

"I have become more involved with CLAPA since Claire's arrival in post as she contacted me and got me interested in becoming an official volunteer and also a parent contact. Before Claire got in contact I hadn't really thought about being a volunteer." -- Parent

"Claire has been a key reason to why I became a volunteer. She is very dedicated and hard working and engages everyone around her." -- Parent

"Before Claire started in post I had little contact with CLAPA and did not feel there was any local support for me. Claire has been the reason I have felt motivated to attend a volunteer induction day and to get involved in local support." -- Parent

"The training I attended was very good and led me to set up the Happy Faces group in Peterborough. Claire has been a fantastic support for this." -- Parent

A number of informal volunteers have also been supported by the RC to provide case stories for the CLAPA website (see appendix 3), to distribute CLAPA posters to local GP and Dental surgeries and to endorse local fundraising events (see section 5). The RC encourages all informal volunteers to complete the formal training, of whom many now have.

1.2. Supporting volunteers

In the past, volunteers have not always felt supported or confident in their role. The RC keeps in regular contact with all current and potential volunteers and endeavours to respond to all queries within a couple of days. Volunteers who have recently completed training receive a formal certificate and are offered the chance to provide anonymous feedback. The RC has attended a number of the newly-established support groups, which she actively promotes. The RC also accompanies Clinic Volunteers on their first time at the NHS clinic to introduce them to the relevant hospital staff and to provide them with ideas and support for initiating conversation with families.

Of those who contributed to the online survey, the vast majority indicated that they felt very well supported by the RC in their volunteering role, with only one person responding 'sometimes'. Respondents also cited finding the RC supportive in their comments.

"Claire made contact with myself and we met shortly after her appointment. Since then, Claire has been very good at keeping in touch with myself as a parent contact." -- Parent

"Claire is very supportive and always quick to respond." -- YP

"I am now interested in setting up a local support group, having been inspired and supported by Claire." -- Parent

"Claire has been very supportive regarding helping me become a volunteer and also in helping me start up a support group in Northampton. She has great energy and is very active in helping others achieve their goals." -- Parent

1.3. Representation and involvement of BME communities

The RC has had significant contact with a number of BME groups over the past year, including:

- The East of England Black and Minority Ethnic Network (MENTER) – a regional network for approximately 420 BME voluntary organisations and communities
- FaithNetEast – an information and learning hub for faith communities
- The English Regions Equality and Human Rights Network (EREN) – comprising strategic Third Sector organization from all English regions
- The Gypsy and Traveller community – e.g. the Travellers Times publication, the Nevitober organisation (focusing on equality in service provision) and the Regional Gypsy and Traveller Empowerment Network

With the help of a BME volunteer, the RC organised and hosted an informal regional event for Asian families. This event was carefully arranged with Asian families in mind, taking important religious and cultural factors into account. Families were identified via the local cleft team and contacted about the event directly. Four families attended the afternoon and provided positive informal feedback. The RC has been in contact with members of these families since and plans to support the running of similar events in the future.

1.4. Enhancing communication

Previous feedback from the various branches indicated a need for closer links between CLAPA National and the regional branches. Focus group data collected from parents of children affected by cleft also demonstrated the need for improved communication between CLAPA and other charities and NHS cleft teams.

The RC has attended all Cambridge Branch Committee meetings and events since she has been in post and has maintained regular contact in between. There have been a number of difficult issues surrounding the Branch Committee. Some of these issues may have been due to the lack of clarity surrounding the RC's role in relation to the branch.

"My expectations about Claire's role as RC were different from CLAPA HQ ideas." – Committee member

However, it appears that many of these issues were pre-existing, with parents reporting that they felt the Branch Committee was "*cliquey*" and had formed a "*club*" which they "*weren't really a part of*." In addition, a number of parents felt the Branch Committee was led by "*dominating*" personalities. Although issues still arise with the Branch, it appears that these are now dealt with immediately rather than lingering, and the branch now have an identified member of staff to contact when necessary. The RC endeavours to handle any conflict appropriately and professionally. In addition, a new Acting Chairperson has recently been appointed to lead the Cambridge Branch.

The RC supported the Branch to organise the annual Summer and Winter Parties, and the CLAPA Annual General Meeting. The RC also keeps in regular contact with the various members of the Cleft Team at Addenbrooke's Hospital in Cambridge.

Participants of the online survey had mixed views of the quality of communication between CLAPA National, CLAPA Branches and other organisations and professionals. This was largely variable according to the participants' location, i.e. those living in or around Cambridge, where both Addenbrooke's Hospital and the CLAPA Cambridge Branch are based, found the communication to be very good, while those living further afield felt less supported.

"We have had excellent support from the NHS Cleft team based at Addenbrooke's. It is sometimes difficult to see where this support ends and CLAPA starts. Both work very well together." -- Parent

"It has been very helpful to have a coordinator and I was able to resolve concerns re: the local CLAPA team which Claire went out of her way to deal with. Having a child with a cleft can be very isolating and Claire provided a bridge back to the local CLAPA branch." -- Parent

"I feel that Claire has bridged the gap in some ways between the head office and local branch support." -- Parent

"I have found it very frustrating that it has not been possible for me to have support more locally. I am unable to travel distances." -- Parent

"Norfolk is such a large county that travelling to Cambridge or Milton Keynes is just too far." -- HCP

"Much stronger links with cleft teams and CLAPA are needed, they almost work against each other." -- Parent

1.5. Branch and volunteers: summary and future directions

The first aim of the RC pilot project was to increase branch and volunteer capacity. During the course of only one year, the RC's work has significantly increased both the number of people interested in becoming a CLAPA volunteer and the number of active volunteers in the region. Many of CLAPA's new volunteers have completed formal training, while existing Parent Contacts have completed 'refresher' training days. Volunteers have enjoyed this training and rated it highly, and have continued to feel well supported over the course of the year. In this way, the RC has been able to inspire confidence in volunteers to head up their own groups and activities, and to provide support to others. The RC has also improved and standardised the volunteering policies and procedures. Initial links have been made with various BME communities, with opportunities to develop these links further. Difficult and ongoing issues with the Cambridge branch have been directly and professionally addressed, and it appears that CLAPA members have benefitted from the changes that have been made. While those living away from Cambridge may feel less supported, the positive impact of localised services is clear for those supported by both Cleft.Net.East and CLAPA's Cambridge branch. This demonstrates not only the potential of local support services, but also the need and desire for those services to be made available elsewhere. Now that the Cambridge branch is successfully increasing its capacity, it is recommended that similar branches and/or local groups be developed in other areas across the region.

Key recommendations

- Continue to recruit and support volunteers to be active in their local area.
- Continue to provide training opportunities for new and existing volunteers.
- Continue to explore and develop links with BME communities.
- Clarify the RC's role in relation to the Cambridge branch and continue to support the Branch Committee.
- Begin to develop other branches and/or local groups in other key areas across the region to provide support to those living outside of Cambridge.

2. Face-to-face support for parents

Following a diagnosis of CL±P, which can be ante- or post-natal, parents often struggle to make sense of the information given to them (Picker Institute 2007). Speaking with other parents who have had similar experiences can provide a great deal of reassurance and contribute significantly to positive adjustment. Although this opportunity is already offered through the CLAPA website, parents are not always aware that this resource is available to them. If they have been made aware, parents are not always confident in making contact with someone they don't know, or would prefer a more personal mode of contact. Having another local parent approach them face-to-face to offer support is a service that many parents have said they would value highly. Similarly, parents have highlighted the worth and importance of swapping experiences of treatment, sharing concerns surrounding their child starting school and dealing with common issues such as bullying and self-esteem as their child grows up. CLAPA identified the need to train more volunteers to provide this support, and the need to create opportunities for parents to meet socially with other local parents of children with CL±P.

2.1. Parent Contacts and Clinic Volunteers

The previous section described how the RC's role has allowed for an increase in the number of active volunteers in the region, as well as a standardisation of training policies and procedures, and an improvement in the ways in which volunteers in the region are supported. These volunteers are currently providing face-to-face support to other parents in a number of ways: as a Parent Contact; as a Clinic Volunteer; and informally via training days, social events and support groups.

Prior to this project, there were only three Parent Contacts in the region. Throughout the pilot year, the RC directly recruited and trained an additional four Parent Contacts. In the past, parents have found this source of support to be immensely helpful, and so having more Parent Contacts on hand is a positive step forward, particularly for those areas that previously did not have any. Additionally, the RC's work revealed that some of CLAPA's existing Parent Contacts reported that they felt "*out of touch*" with current services and treatments and consequently were not in a position to offer information. Parent Contact Refresher Training has therefore been implemented (also see section 1).

The original suggestion for having volunteers in the cleft clinics was developed with CLAPA members and has now been implemented by the RC. Six volunteers are now attending clinics across the region, to meet and greet parents and to offer support and information. One parent commented that the volunteer who attended her clinic was "*very helpful and engaging*" and that having volunteers in the clinic was "*very positive and proactive*" and "*really helped*" her and her son to get through a long day of hospital appointments.

Several more people have since expressed their interest in becoming a Parent Contact and/or a Clinic Volunteer. The RC endeavours to follow up all enquiries and requests within a couple of days, and to encourage and support potential volunteers to achieve their aims.

There was some conflict between parents over what type of support they wanted and from whom.

"The Parent Contacts are not a substitute for professional advice and...they are perhaps not the best people to be giving advice as they are so emotionally involved." -- Parent

"It would have been useful to have more parent contact in the first year. The cleft team are brilliant but they offer professional advice." -- Parent

"Other mums 'just get' what [I] am talking about." -- Parent

First, it is important to ensure that all Parent Contacts and Clinic Volunteers are required to undertake the appropriate training, to emphasise what the boundaries are and when they need to signpost parents to other sources of support. As previously described, the RC is now able to implement this in the East of England region. It should also be made clear to all parents that this is the case, so that the Parent Contacts are a known source of reliable support. Second, a much clearer distinction should be made between the support that is available from HCPs and that which is available from CLAPA volunteers. Specifically, that each group will have a different level of knowledge, and that volunteers are in place to offer additional support for those who need it, when they need it, and are not there to replace professional advice in any way.

2.2. Social events and support groups

The Happy Faces support groups provide a chance for local parents to offer support to one another. Although primarily aimed at young people, the East of England Young People's group also facilitates these opportunities. Similarly, both the social events and fundraising events create opportunities for parents to socialise and share experiences with others living in their local area. More information about the events held during the pilot year is provided in section 3.

In responding to the online survey, parents indicated that they had attended a number of these different events over the past year, and found them useful and enjoyable. Others were enthusiastic about establishing new groups.

"[The events] Are a good way of meeting families going through the same experiences that we are and sometimes finding people living near you that you didn't know about." -- Parent

"I am in the process of setting up a Happy Faces group in Northampton...our first meeting is in January 2012." -- Parent

"Have discussed the possibility of setting up a Norwich group with Claire previously – I would still be very interested in doing this." – Parent

As demonstrated by a number of the case studies, other parents had mixed feelings about the parties that had been run <u>before</u> the RC was put in post.

"The parties are aimed more for the children and so tend to revolve around something like a disco and therefore it is not the easiest place to communicate due to the loud music." -- Parent

"A number of parents [I have] previously spoken to have said they do not attend Cambridge Branch Parties because they are held at Addenbrooke's and they and their children associate Addenbrooke's with treatment." -- Parent

It is therefore essential that all events held in the region are accessible to all those individuals they are intended for.

Some parents had various ideas for future events and coffee mornings were particularly requested.

"Local weekly coffee mornings." -- Parent

"It would be good if...there were some more meetings or coffee mornings in the area for parents to meet in a relaxed atmosphere as it is sometimes easier to chat to other parents and bring up issues away from the clinics." – Parent

The RC could not only incorporate these ideas into future CLAPA projects, but encourage the parents to organise and run these events themselves. Indeed, since these comments were made at the beginning of the pilot year, parents have used the new regional Facebook page to locate other parents in their area and to arrange face-to-face meetings. Where this occurs, the RC always offers the opportunity for these parents to become official volunteers and to set up an official Happy Faces group in their area.

As before, the issue of distance was of concern for parents, and in some cases this prevented them from attending some of the events.

"It is hard for me to get away. If there was something a bit closer I would attend." -- Parent

"The Summer event was good, but a bit far to travel. There are never any events in Norwich or anywhere nearby, there are a number of families in this area that would be interested in events if made more accessible." -- Parent

This further illustrates the benefits of continuing to extend the local support that is available to all areas of the region.

2.3. Parents: summary and future directions

The RC has been able to recruit and train new Parent Contacts and support them to volunteer in areas which previously did not have this service. She has also implemented Parent Contacts Refresher Training, which has been beneficial for those who were relatively inactive when the RC arrived in post, and reflects good ongoing practice. The RC was able to implement the idea of having volunteers within the cleft clinics, which has had apparent benefits for those giving and receiving this type of face-to-face support. However, the role of the Parent Contact/Clinic Volunteer in contrast to other potential sources of support (such as HCPs) should be made explicit. This activity has also raised more interest from potential volunteers in the region, and across the UK. Parents are clearly enthusiastic about the organised social events and support groups, but these need to be made as accessible as possible. Parents also seem to value having the resources to arrange their own informal meetings, away from hospitals and formal events. Distance is an issue for parents, who may not attend social events and groups if they are only held in certain 'key' areas.

Key recommendations

- Continue to recruit, appropriately train and support Parent Contacts and Clinic Volunteers to be active in their local area.
- Continue to support volunteers to run and attend local support groups.
- Continue to support the organisation of formal and informal social and fundraising events, and endeavour to make such events as accessible as possible by involving users in their design.
- Expand these local networks to all major areas within the region, to ensure that all parents have equal opportunities to attend support groups and events.
- Clarify the roles of volunteers and the limits of the support that they can provide.

References

Picker Institute (2007). *Information needs for people living with conditions that affect their appearance*. Final Report.

3. Building social networks for children and young people

It is very often the case that children and young people born with CL±P have never met anyone else with a cleft until they attend a CLAPA event. Up until 2010, CLAPA held an annual summer camp for children with CL±P, where children are able to meet and talk with other children who have had similar experiences. As a result, there is no need for them to explain why they look or sound 'different', and they can swap stories informally and learn from one another. CLAPA has had much success with this annual event in the past, and both parents and camp attendees have commented on how invaluable the experience has been in terms of raising self-esteem, gaining confidence and improving social skills. CLAPA members have previously asked for these types of events to be held locally, and more frequently, to help children and young people to build up a local social network.

3.1. Residential weekends

Rather than offering an annual summer camp, CLAPA now run regional residential weekends, to enable children and young people to build up a local social network with other children born with CL±P. The RC has played a key role in this, particularly in regard to the advertising of these events.

3.2. Social events and support groups

The RC was involved in supporting a number of existing social events (such as those annually hosted by the Cambridge Branch/Addenbrooke's Hospital), as well as the organisation of several new events. Some of these social events were open to families, with children and young people of all ages attending, whereas others were organised with input from the newly established East of England's Young People's group, and were specifically aimed at young people. The new Happy Faces groups and the re-established Children and Young People's Council also met during the pilot year. A list of these different events is displayed below in Table 3.

Table 3: Social events and support group meetings with children and young people attending.

Event	Date held	Location	Target group	Organiser
East of England Young People's Group	July 2011	Bedford	Young people aged 11-16	The RC
Summer Party	July 2011	Cambridge	Families	CLAPA Cambridge Branch / the RC
Peterborough Happy Faces Group	Every month, starting in August 2011	Peterborough	Families	Parent Contacts / the RC
East of England Young People's Group	August 2011	Ely	Young people aged 11-16	The RC
Silverstone Social Event	September 2011	Silverstone	Families	CLAPA donor
Milton Keynes Happy Faces Group	Every month, starting in September 2011	Milton Keynes	Families	Local volunteers / the RC

Asian Families Event	October 2011	Luton	Families	The RC / local volunteer
East of England Young People's Group	December 2011	Northampton	Young people aged 11-16	The RC
Winter Party	December 2011	Cambridge	Families	CLAPA Cambridge Branch / the RC
Children and Young People's Council	December 2011	London	Children and young people aged 9-17	The RC
Northampton Happy Faces Group	Every month, starting in January 2012	Northampton	Families	Parent Contact / the RC

A full report of both the Summer and Winter Parties is available in the appendices. The feedback from the Summer Party was used to inform the organisation of the Winter Party, and the RC has made a number of recommendations for the organisation of next year's parties, based on the feedback received. A new Happy Faces group is also currently being established by a Parent Contact in Cambridge.

Of the parents who responded to the online survey, several had attended the Happy Faces groups and had children who had also attended these groups, as well as the East of England Young People's group. Parents mostly rated these groups as 'good' or 'very good', although four parents (out of 40) rated the groups as either 'fair' or 'poor'. The vast majority of parents felt that setting up a support group based in their, and/or other local areas would be beneficial, although again a few discrepancies were observed. One possible reason for this is that some parents were concerned that having specialist cleft groups may draw their child's attention to the cleft, or result in them feeling 'labelled'. Some parents felt these groups weren't relevant/currently relevant to their families.

"At the moment he is only 5, and doesn't see his lip as a problem. I would have reservations about attending any cleft event in case it made him more conscious of this. If he had problems in the future I may well change my views though!" -- Parent

"Support groups would be good for kids approx. age 10 when other people start to notice differences. Until then they don't seem to realise there's anything different about them." -- Parent

"Would depend if J wanted to be a part of a group as he is very happy at the moment and has a great friendship group at his new school." -- Parent

Only one parent had had an unfortunate experience. Other parents were very enthusiastic about the local groups.

"They need to be accessible to all...and much better organised...the groups don't feel very welcoming, which is a real shame." -- Parent

"My son was not able to attend the previous meeting but has been looking forward to attending in December." -- Parent

"I hope these groups are still available when my daughter grows up. I think they're invaluable and fab." -- Parent

The choice to attend cleft-specific events and join support groups appears to be individual to each family. It is probable that those parents who feel their child is currently struggling to adjust would be more likely to encourage their child to attend.

Issues surrounding travel were raised once more.

"Once again, representation in Norwich would be welcomed."

HCPs completing the online survey indicated that a number of their patients were currently attending the various local groups across the region. The majority of HCPs believed that these groups would be of benefit to their patients and that establishing more groups across the region was a positive move forward. When answering the open-ended question 'Is there anything more the RC could be doing to improve local services in your area?', one HCP commented similarly on the potential problem of holding isolated events:

"Integration of cleft children to mainstream events rather than just segregated events." -- HCP

None of the young people who responded to the online survey had currently attended the East of England Young People's support group as the group is relatively new, but liked the idea of having a local group and were interested in attending in the future. The idea of including siblings in this group was also raised.

"[Name] being born with a cleft has had a knock on effect on her older sister...although [we] try very hard not to let it, numerous hospital visits ultimately has an effect on family life and what her sister is able to do." -- Parent

"...it would be nice for them (siblings) to get some recognition, relax and talk to other children who understand, just like parents need to do." -- Parent

A testimonial from a young person's sibling can also be found in the appendices.

In addition to these social groups and events, the RC recently re-launched the CLAPA Children and Young People's Council. There are currently 8 members, aged between 9 and 17 years.

Those young people who responded to the online survey offered a number of additional comments.

"Claire is always very approachable and easy to speak with, whilst being empathetic." -- YP

"Having met Claire on many occasions she is a very lovely and approachable person. Having someone there to help support CLAPA in our area and promote help for young people who have cleft lips is amazing and can give people the confidence to realise that they are not on their own! Claire is doing a great job!!" -- YP

3.3. Children and young people: summary and future directions

The RC has been involved with a number of existing and new social events and support groups for children and young people during the pilot year. Although the East of England Young People's Group and the Children and Young People's Council are new, positive feedback about the idea of having these groups has been received. Respondents of the online survey had mixed feelings about cleft-specific social events, and choosing which events to attend and at what time point appears to be different for each family. However, this issue was not raised by the young people themselves. Further investigation of this topic may be needed to improve accessibility. Distance was once again identified as being problematic.

<u>Key recommendations:</u>

- Continue to support volunteers to run and attend local groups.
- Continue to support the organisation of social events for children and young people, and endeavour to make such events as accessible as possible by involving users in their design.
- Expand these local networks to all major areas within the region, to ensure that all children and young people have equal opportunities to attend support groups and events.
- Consider including children without a cleft, such as siblings, in some events, as well as the addition of an online forum/discussion board for siblings of young people with CL±P.

4. Support for adults with CL±P

CLAPA has identified a real and unmet need to reach the adult CL±P population. Prior to the reorganisation of cleft care in the late 1990s, many patients felt they had received substandard surgical care and emotional support. CLAPA frequently receives requests for help and advice from adults who are dissatisfied with the treatment they received, and as a result are still unhappy with their facial appearance and/or speech. This can have very real and widespread consequences on adults' psychological wellbeing and social relationships (Rumsey and Harcourt 2005). In addition, the NHS cleft care pathway typically ends between the ages of 18-21 years; the support that has been present for all of the patient's life may not be as accessible in adulthood. Previous feedback has indicated that many adults feel neglected in terms of the support they receive and in the past have not known where to turn for help or advice.

4.1. The Adult Council

CLAPA's adult council was established in 2010 to enable adults who were born with CL±P to take an active part in shaping cleft services and to provide a regional presence. As the CLAPA representative for the region, the RC liaises with the Adult Council on a regular basis. Her aims include helping to bridge the gap between the Adult Council and the National CLAPA office, to provide support to the Adult Council to action their goals, and to encourage new members to join. The RC also hosted the most recent Adult Council meeting in the East of England region. Two existing members of the Adult Council provided testimonials, which are provided in full in the appendices.

4.2. Adult volunteers

In the past, adults have either not been aware of the support services available to them through CLAPA, or have had to 'refer themselves' to get any kind of support. The RC has made contact with an additional 16 adults and has recruited and trained two adult volunteers from the region. It is anticipated that this number will continue to grow through promotion of the opportunities now available to adults locally.

A small number of adults from the region with CL±P completed the online survey. It was very apparent that the support they had received in the past had been very minimal, and that the idea of local support for adults with CL±P clearly appealed to them.

"Growing up I never received any information to help with emotional support, I did not know this was even out there until now." -- Adult with CL±P

"Having been born in the 70's, at that time there was minimal support available...Having previously referred myself...I have been amazed at how much accessible support there is available." -- Adult with CL±P

4.3. Adults: summary and future directions

The RC's role seems particularly welcome in this area. She is able to provide the Adult Council with a broad understanding of what is happening within the region, and around the UK. This has allowed them to feel more a part of CLAPA and become more actively involved. The RC has also recruited adult volunteers, who can provide another level of support to both adults born with CL±P and families.

Key recommendations:

- Continue to inform and support the Adult Council to achieve their aims.
- Continue to promote the Adult Council and encourage new members to join.
- Continue to recruit adult volunteers in the region.
- Continue to raise awareness of the growing support available to adults with CL±P.

References

Rumsey, N. & Harcourt, D. (2005). *The Psychology of Appearance.* Open University Press.

5. Raising awareness of CL±P and CLAPA

Despite CL±P being the most common congenital craniofacial condition, public awareness of CL±P is surprisingly low. CLAPA often hear from parents that they knew nothing about CL±P prior to having their child diagnosed, and that better awareness of the condition would help parents to make sense of the diagnosis. Other parents report negative reactions from members of the general public, which can be particularly upsetting. These reactions are often due to a lack of knowledge of CL±P. A better public appreciation of CL±P would increase understanding and improve responses to the condition. Raising the profile of CLAPA would also make more people aware of the support that is available for those affected by CL±P.

5.1. Awareness-raising activities

The RC has led and been involved with a number of awareness-raising efforts. She is highly active on several social networking websites, and has set up her own Facebook page to complement the main CLAPA Facebook page, both of which she contributes to daily. The RC uses the sites to promote events, training dates and research in the East of England and across the UK. The sites are very popular, with over 2,000 members, and act as a source of awareness-raising and social support, allowing members to share experiences and offer advice. The RC is also an active member of the CLAPA and FaceForward online forums, which are aimed at parents, and young people and adults with CL±P.

The RC has facilitated and attended several events across the region, which have been targeted at raising awareness of CL±P. These events have attracted hundreds of participants, invited media attention and helped to raise funds for CLAPA. A number of these events were held during Cleft Lip and Palate Awareness Week 2011, which is specifically aimed at educating the general public about the condition. The RC is now helping to organise a number of activities in the region to take place during the next Cleft Lip and Palate Awareness Week (May 2012). A list of these events is displayed below in Table 4.

Table 4: Awareness-raising and fundraising events held in the region

Event	Date held	Location	Target group	Organiser
Fashion show fundraiser / cheque presentation	April / May 2011	Towcester	Families / local community	Towcester Town Council
Participation in the Waendel Walk	May 2011	Wellingborough	General public	The RC / local volunteers
Peterborough fundraiser	May 2011	Peterborough	Families / local community	Local volunteer / the RC
Charity Fun Day	August 2011	Wellingborough	Families / local community	Local volunteers

The RC has also written articles for the local press, and encouraged several volunteers to do the same. Printed in popular local media and displayed online, these articles have promoted various events taking place in the region, and helped to raise awareness of CL±P and CLAPA more generally.

The RC has supported volunteers to distribute posters to GP and Dental surgeries throughout the region, to further raise awareness of CL±P and the support that CLAPA provides. Currently, volunteers have displayed posters in 16 different medical centres, with more distribution efforts planned for the coming months.

The RC has formed strong links with a number of schools in the region, and conducted presentations about CL±P and the work CLAPA do to both school staff and pupils. For two of the schools, raising awareness of CL±P was particularly pertinent, as they either had staff who were parents of children with CL±P, or had pupils attending the school who were born with CL±P themselves. In one school, a Mufti Day was held to raise money for CLAPA and Children in Need.

The RC has also presented at a number of professional meetings and conferences, including cleft-specific events and more general professional events (also see section 6).

5.2. Awareness: summary and future directions

The RC has been extremely active in raising awareness of both CL±P and CLAPA, using a variety of different media and activities, directed towards a wide range of audiences. These activities are not only important to alert and educate the general public about the condition, but also to empower volunteers to raise awareness and share their experiences with others.

Key recommendations

- Continue to manage and play an active role in social networking websites and awareness-raising events in the region.
- Continue to publicise CL±P in the local press, at local GP and Dental surgeries and within schools.
- Continue to run regional events during Cleft Lip and Palate Awareness Week and ensure this enthusiasm is maintained across the year.

6. Training and support for Healthcare Professionals (HCPs)

Families affected by CL±P have identified a lack of understanding and support from non-cleft specialist HCPs in relation to diagnosis and treatment. Parents have described situations in which a sonographer or midwife has left the room due to being unable to deal with the situation, or has given inaccurate information leaving parents confused and scared. Parents also commonly report quickly being offered a termination without having full information on the implications of the condition, or without a referral to the specialist cleft teams. In addition, cleft palates are extremely difficult to detect using current scanning techniques, and a high percentage of cleft palates are not diagnosed until a long time after birth. This is likely to lead to feeding problems, nasal regurgitation, faltering growth and the possibility of hospital readmission. Correct diagnosis and appropriate support throughout treatment can be pivotal to parents in terms of developing confidence in themselves as parents, and also in their confidence in HCPs' ability to help.

6.1. Cleft teams and voluntary organisations

As previously described, the RC has made and enhanced links with the various NHS cleft teams around the UK, and a number of other voluntary organisations, such as Changing Faces, the National Osteoporosis Society and the National Deaf Children's Society. The RC's aims in relation to this are to promote CLAPA, to keep stakeholders informed of progress, to explore the potential to work in partnership and to share best practice. CLAPA also encourage cleft teams to work with HCPs informally, for example, by visiting midwifery units. A list of major meetings and activities is provided below in Table 5.

Table 5: Links with HCPs and voluntary organisations

Organisation	Date	Link
National Osteoporosis Society	February 2011	Sharing best practice
Cleft.NET.East Team	March 2011	Attended team meeting/met with Lead Clinical Psychologist
National Deaf Children's Society	March 2011	Sharing best practice/working in partnership
Cleft.NET.East	March 2011	Catch up meeting with Lead Clinical Psychologist
Cleft.NET.East Clinical Nurse Specialists	April 2011	Attended team meeting
Changing Faces	May 2011	Met CF Regional Coordinator/working in partnership
Luton and Dunstable Hospital	May 2011	Attended cleft clinic
Kettering General Hospital	May 2011	Registered as official hospital volunteer/attended cleft clinic
Bedford General Hospital	May 2011	Attended cleft clinic/attended team meeting
Changing Faces	June 2011	Attended Study Day
Cleft.NET.East Clinical Nurse Specialists	June 2011	Attended team meeting
Cleft.NET.East	June 2011	Catch up meeting with Lead Clinical Psychologist
Addenbrooke's Hospital	July 2011	Attended cleft clinic
Cleft.NET.East	July 2011	Presented at multi-professional meeting

Kettering General Hospital	July 2011	Attended cleft clinic
Addenbrooke's Hospital	October 2011	Attended cleft clinic
Bedfordshire Speech and Language Service	October 2011	Attended NHS Speech and Language Day and set up a stand to promote CLAPA
Ipswich Hospital	October 2011	Attended cleft clinic with a CLAPA volunteer
Peterborough Hospital	November 2011	Attended cleft clinic with a CLAPA volunteer
Cleft.NET.East	December 2011	Meeting with Clinical Psychologists and Cambridge Branch

HCP respondents to the online survey felt that the RC Project was generally a positive and beneficial initiative, and that the RC was someone with whom they could have a collaborative and supportive working relationship. However, there was some caution in regard to the RC providing emotional support without Psychological or Counselling training.

"I'm not sure if they should be providing emotional support??" -- *HCP*

"It should have been someone with more experience in cleft/someone who has had Psychological training." -- *HCP*

It is essential that the RC knows the limitations of the support they are able to provide. It is therefore recommended that CLAPA consider actively recruiting Regional Coordinators with experience of delivering emotional or peer support, and/or help to develop counselling/listening skills as part of their package of training and supervision. In the meantime, it is recommended that CLAPA continue to liaise with CAR if any issues or concerns arise.

6.2. Awareness-raising

As described in section 5, the RC has been involved in a number of awareness-raising efforts, many of which are aimed at non-specialist HCPs. The RC has also encouraged volunteers to give presentations to interested groups about CL±P, such as trainee midwives. Volunteers have been actively involved in this process and are eager to do more. The RC has also been in contact with sonographers at one hospital in the region and is keen to carry this forward.

6.3. Training for non-cleft specialist HCPs

CLAPA had previously developed a training pack for HCPs to directly tackle these common issues and therefore improve the support available to parents. It is hoped that the training pack can soon be reviewed and the training be delivered, although CLAPA are currently lacking the resources needed to achieve this. It is highly recommended that CLAPA endeavour to provide standardised formal training across the UK for non-specialist HCPs in the future. However, it must be recognised that this is a difficult task which will take some time to implement.

6.4. HCPs: summary and future directions

The RC has made a promising start in this particularly challenging area. Links with relevant stakeholders have been made and strengthened, and both the RC and CLAPA volunteers have been raising awareness of the condition amongst non-cleft specialist HCPs informally. Much more could be done in this area, and is considered to be a priority for future work.

<u>Key recommendations:</u>

- Continue to raise awareness of CL±P with non-cleft specialist HCPs, and to encourage volunteers to do the same.
- Consider implementing a basic level of counselling/listening skills training for all those staff working closely with vulnerable groups.
- Work with specialist cleft teams to review, pilot, evaluate and implement standardised, formal training for non-cleft specialist HCPs in this region and across the UK.

7. Promoting and supporting user involvement

User involvement is becoming increasingly important in research and practice (INVOLVE 2009). CLAPA is dedicated to increasing the number of active volunteers across the UK, to supporting NHS cleft teams to involve users in the evaluation and development of their services, to collecting and actioning feedback on their own services, and to training and supporting users to become representatives in NHS board meetings and to take part in high quality research. The RC has worked closely with CLAPA's User Involvement Lead to support and implement these aims in the East of England region.

7.1. Case studies

In the early days of her post, the RC spoke with a number of cleft service users, to gain the user perspective on the support that was available at the time. As part of this and with users' permission, the RC collected 17 case studies. These case studies, along with previous work by CLAPA and the focus group findings described below helped to direct her work over the pilot year, and ensure the work she carried out was applicable and beneficial to users of cleft services. An example of one such case study is provided in the appendices.

7.2. Focus group recommendations and implementation

The RC pilot project was initially instigated because users of cleft services indicated they would like to receive more support on a local level. Soon after the project commenced, the RC assisted CAR in the facilitation of a focus group. As previously described in the introduction to this report, the aim of the group was to establish what users wanted from local support specifically, to help CLAPA to appropriately direct their efforts. The main recommendations made by users during this focus group are listed below, followed by details of how the RC has since actioned each point within the East of England region.

Continue to make feeding advice and equipment available in all clinics and via the website
The RC has liaised with the regional cleft teams to ensure that high quality and consistent feeding advice is available at each clinic. The RC has also ensured that the different websites she is involved with are constantly being improved and updated to make them as accessible and easy to use as possible.

Increase the availability of pre-natal 3D scans in routine care and improve knowledge and practice in the detection of cleft palate
The RC has supported CLAPA in their continued campaigning in this area and has provided literature and support for those parents receiving an antenatal diagnosis. 3D scans have also been implemented in the East of England.

Implement standardised training for generic HCPs and teachers
The RC has been actively involved in the development of training information and complementary literature, and has presented at a variety of events and conferences (also see sections 5 and 6).

Identify the key players in the local area and support the coordination of cleft care to improve communication and the consistency of information given to families

The RC has encouraged volunteers to raise awareness of CL±P and CLAPA in their local GP and Dental surgeries, not only to promote understanding of the condition to the general public, but also to non-cleft specialist HCPs. The RC has also made links with the relevant NHS cleft teams in hospitals across the region and liaises directly with each of the clinic coordinators. She has encouraged each team to display CLAPA literature within their units over the past year and has attended numerous cleft clinics herself. The RC has trained and supported volunteers to attend cleft clinics at four different hospitals and to speak with and distribute literature to families waiting for appointments (see sections 1 and 2).

Increase collaboration with other charities and professional bodies

The RC keeps in regular contact with other relevant charities, such as Changing Faces and the National Deaf Children's Society, in order to share best practice and support one another. She has also made links with various BME community groups. The RC also consults regularly with CAR (see sections 1 and 6).

Increase the psychosocial support available following the first two years after birth

Parents often feel that the support from the cleft teams '*tails off*' after the first year or two. The RC has liaised with NHS cleft teams regarding the provision of Clinical Psychology for patients and parents, and endeavoured to increase the level of support available for all age groups (see section 6) and in relation to a number of key 'milestones'. She has also trained a number of Parent Contacts to provide emotional peer support and signpost their peers to the relevant HCPs when necessary.

Implement training in basic counselling skills for CLAPA staff

The RC has attended training offered by the charity Changing Faces, which was aimed primarily at health and social care professionals and explored the psychological and social aspects of disfigurement. The RC has benefitted from involvement in the Parent Contacts Training, which focuses on boundaries, listening skills and relevant case scenarios. She is also able to liaise with CAR on any psychological issues which arise.

Increase the number and quality of local support groups and social events for children and parents

Three groups have now been established in the region, with one more currently being set up. A number of training and social events have been held during the pilot year, which have been described in more detail within previous sections of this report (see sections 2 and 3). To ensure the quality of service provision at all times, CLAPA members are only permitted to set up local groups once they have undergone the new checks and become an official CLAPA volunteer. The Cambridge branch is also now supported to create and follow risk assessments for all of their events.

7.3. CLAPA Councils

As previously described (see section 4) the RC has been in regular contact with the Adult Council, and has re-launched the Children and Young People's Council. Both councils are committed to taking an active part in shaping cleft care and providing a regional presence, and are actively supported by the RC to accomplish their aims.

7.4. Research

Supporting people to take part in research is beneficial for all involved. Those who participate often enjoy the opportunity to share their experiences and feel empowered that their participation will benefit others. Those conducting the research learn invaluable information which helps to inform practice and to direct future projects. The RC has been an important asset in promoting and recruiting participants to take part in a number of CL±P research projects and initiatives.

7.5. User involvement: summary and future directions

The RC has upheld and actively contributed to CLAPA's user involvement policy. She collected a number of case studies and was involved in the initiation and facilitation of a focus group with parents, the findings from which formed the basis of much of her work over the pilot year. The RC has played a key role in implementing these initial recommendations, while also exchanging ideas with adults and young people with CL±P, to ensure that all users are appropriately supported.

Key recommendations

- Continue to collect and appropriately respond to feedback from all those involved with and affected by regional cleft care.
- Continue to support the Adult, and Children and YP Councils.
- Continue to promote research and training events in the region.

References
INVOLVE (2009). *Good practice in active public involvement in research*. Accessed online March 2012. http://www.invo.org.uk/wp-content/uploads/2011/11/GoodPracticeA52009.pdf

8. Overall evaluation of the CLAPA Regional Coordinator role

As part of the online survey, participants were asked to rate the impact of the RC role overall. The results were overwhelmingly positive and can be viewed below in Table 5.

Table 5: Overall evaluation of the Regional Coordinator role during the pilot year

	PARENT	YP/ADULT	HCP	TOTAL
Overall, **how beneficial** do you think it has been to have a CLAPA Regional Coordinator in your area?	Very = 17/36	Very = 4/7	Very = 6/11	Very = **27/54**
	Quite = 6/36	Quite = 0/7	Quite = 3/11	Quite = **9/54**
	Somewhat = 5/36	Somewhat = 0/7	Somewhat = 1/11	Somewhat = **6/54**
	Not very = 2/36	Not very = 0/7	Not very = 0/11	Not very = **2/54**
	Not at all = 0/36	Not at all = 0/7	Not at all = 0/11	Not at all = **0/54**
	Don't know = 6/36	Don't know = 3/7	Don't know = 1/11	Don't know = **10/54**
Would you like a CLAPA Regional Coordinator in your area more **permanently**?	Yes = 25/32	Yes = 6/7	Yes = 8/11	Yes = **39/50**
	Maybe = 5/32	Maybe = 1/7	Maybe = 3/11	Maybe = **9/50**
	No = 0/32	No = 0/7	No = 0/11	No = **0/50**
	Don't know = 2/32	Don't know = 0/7	Don't know = 0/11	Don't know = **2/50**
Do you think a CLAPA Regional Coordinator should be introduced in **other regions** in the UK?	Yes = 26/36	Yes = 7/7	Yes = 8/11	Yes = **41/54**
	Maybe = 6/36	Maybe = 0/7	Maybe = 2/11	Maybe = **8/54**
	No = 0/36	No = 0/7	No = 0/11	No = **0/54**
	Don't know = 4/36	Don't know = 0/7	Don't know = 1/11	Don't know = **5/54**
Do you think the Regional Coordinator is someone who: can provide **practical support and information**?	Yes = 26/31	Yes = 6/7	Yes = 11/11	Yes = **43/49**
	Maybe = 0/31	Maybe = 0/7	Maybe = 0/11	Maybe = **0/49**
	No = 0/31	No = 0/7	No = 0/11	No = **0/49**
	Don't know = 5/31	Don't know = 1/7	Don't know = 0/11	Don't know = **6/49**
Do you think the Regional Coordinator is someone who: is **friendly and approachable/ collaborative and supportive**?	Yes = 30/36	Yes = 7/7	Yes = 11/11	Yes = **48/54**
	Maybe = 0/36	Maybe = 0/7	Maybe = 0/11	Maybe = **0/54**
	No = 0/36	No = 0/7	No = 0/11	No = **0/54**
	Don't know = 6/36	Don't know = 0/7	Don't know = 0/11	Don't know = **6/54**
Do you think the Regional Coordinator is someone who: can provide **emotional support**?	Yes = 17/36	Yes = 5/7	Yes = 9/11	Yes = **31/54**
	Maybe = 0/36	Maybe = 0/7	Maybe = 0/11	Maybe = **0/54**
	No = 5/36	No = 1/7	No = 2/11	No = **8/54**
	Don't know = 14/36	Don't know = 1/7	Don't know = 0/11	Don't know = **15/54**
Do you think the Regional Coordinator is someone who: can **represent parents', patients' and HCPs' views**?	Yes = 25/35	Yes = 6/7	Yes = 10/11	Yes = **41/53**
	Maybe = 0/35	Maybe = 0/7	Maybe = 0/11	Maybe = **0/53**
	No = 3/35	No = 1/7	No = 0/11	No = **4/53**
	Don't know = 7/35	Don't know = 0/7	Don't know = 1/11	Don't know = **8/53**
Do you think the Regional Coordinator is someone who: can **raise awareness** of CL±P?	Yes = 31/36	Yes = 7/7	Yes = 11/11	Yes = **49/54**
	Maybe = 0/36	Maybe = 0/7	Maybe = 0/11	Maybe = **0/54**
	No = 1/36	No = 0/7	No = 0/11	No = **1/54**
	Don't know = 4/36	Don't know = 0/7	Don't know = 0/11	Don't know = **4/54**

Participants of the online survey were also invited to share any other comments they had about the RC's role. Again, these comments document the positive impact of local support delivered by the RC and a selection of these responses is provided below.

"When my son was born 17 years ago I didn't feel I had enough local support other than my GP, however since meeting Claire the support is now out there for families which is fantastic." -- Parent

"My support stopped in Denmark when I was 19 and moved to England. I have had no support from doctors/dentists here ever since. I only discovered CLAPA last year and didn't actually know that there was a support team until Claire." -- Adult with CL±P

"Claire is efficient, warm, supportive and practically focused. She gets things done and speaking from personal experience I think she has made a huge impact on support from those affected by cleft in the East of England." -- Parent

"Claire is not only helpful but is prepared to listen to others' views and opinions in order to pull together ideas for promoting awareness. I think it has been a difficult task to establish events but I am confident that if this post remains that parents, carers and patients will have access to a very useful resource which crosses a host of organisations and helps to support you to find answers to your questions/concerns." -- Parent

"Without Claire we would not have met the people we have and we are very hopeful for the future with a coordinator around. Please can we keep her!!!" -- Parent

Finally, participants of the online survey were asked to indicate what more, if anything, the RC could do to improve local services. A number of participants made some interesting suggestions. Alongside this, there was again some confusion over the role of the RC.

"Educate GPs on cleft-related issues and practicalities." -- Parent

"They could help to raise awareness of cleft babies in more schools so that they know where to turn to for help and assistance should they have a pupil join with a cleft." -- Parent

"To visit the individual larger towns regularly and inform people when she's there so people can go along and raise points or ask questions." -- Parent

"I'm not sure what is done and how this compares to what was being done before the role was in place." -- Parent

"I don't know what a Regional Coordinator is or what they are meant to do." -- Parent

"I wish I knew more about them, and what it is they have done/been doing. Sounds like a great idea and something I would be supportive of." -- Parent

Those who had had direct contact with the RC during the pilot year were invited to send an anonymous testimonial to CAR. These are provided in the appendices.

9. Final summary and recommendations

9.1. Final summary

The main aims of the RC pilot project were as follows:

1. To increase branch and volunteer capacity
2. To provide face-to-face support for parents
3. To support children and young people to build social networks
4. To provide support for adults with a cleft
5. To raise awareness of CL±P amongst the general public
6. To provide training and support for non-cleft specialist HCPs
7. To promote and support user involvement

The RC Project has achieved a great deal throughout the course of the pilot year and significant progress has been made in relation to each of the initial aims.

The amount and range of volunteering activity has significantly increased and diversified within the region. The RC was able to engage with existing volunteers, as well as successfully recruit and formally train several new volunteers, all of whom are now actively contributing to CLAPA's regional activities in a variety of ways. Importantly, volunteers feel empowered to provide information, advice and support to others with confidence. They enjoy their role and aspire to contribute further. Those individuals who have received support in the past want to 'give back' and go on to help others in the same way, thus creating a potentially self-sustaining network.

The RC forged and enhanced links with hard-to-reach communities, local schools, NHS cleft teams and a variety of different charities and organisations, both within the region and across the UK. Positive feedback from each of these has been received. Working with the Cambridge Branch has been challenging, and it is recommended that the role of the RC be clarified.

The RC has been involved in the organisation and facilitation of a great number of social events and support groups, aimed at parents, children, young people and adults affected by CL±P. While some of these events could be improved, general opinion has been largely positive, and users' feedback has guided the development of future events. The RC has re-launched the Children and Young People's Council and effectively supported the development of the Adult Council.

Raising awareness has been another key strength of the RC, who has been actively involved in a number of awareness-raising and fundraising projects and events. Crucially, she has encouraged and supported volunteers within the region to do the same.

User involvement has been fundamental to this role and has been applied extremely well. The user perspective formed the initial development of the role itself, and the basis of the RC's work throughout the pilot year. Ongoing feedback has been collected, documented and actioned. User opinion has also been central to this evaluation.

Of those who responded to the online survey, the majority felt that the RC role had been beneficial to them, should be permanently implemented within the East of England region and should be introduced gradually into other regions across the UK. The RC was seen as someone who had the potential to provide practical support and information and emotional support, was friendly and approachable, could accurately represent users' views and could actively contribute to raising awareness about CL±P.

9.2. Key areas for development

Although initial steps towards supporting and training HCPs has been made, this is considered a priority area for future work. The review, development, evaluation and implementation of standardised, formal training for non-cleft specialist HCPs, as well as ongoing informal awareness-raising is recommended. This is a difficult task and one which is likely to take some time, but one which the RC may play a key role in.

Similarly, it is recommended that all staff engage in a basic level of counselling/listening skills training if working closely with vulnerable groups, which should be annually reviewed and refreshed.

The potential impact of localised services is clear, as is the need for these services to be made widely available. Ongoing development of the existing Cambridge Branch is recommended, as is the gradual development of other Branches and/or local groups within the region and across the UK. The RC role appears to be highly valued, and offers a great deal of potential. However, it is suggested that the RC role be clarified to evade confusion, and to avoid the overlap of roles.

Lay summary

Having a baby diagnosed with a cleft lip and/or palate (CL±P) can be an upsetting time for parents. Ongoing treatment can also be stressful, and parents often have concerns about their child's future. Being born with a cleft may also affect the child as they grow up, particularly if they have concerns about their appearance or speech. Some people who were born with CL±P before the standard of cleft care was improved may be unhappy with the treatment they received and not know where to turn for advice. Having access to appropriate support when it is needed is vital in helping people to cope positively with the impact that the cleft might have on their lives. The Cleft Lip and Palate Association (CLAPA) provide support to anyone affected by CL±P in the UK. Although they already provide a valuable service nationally, they have received widespread requests to implement this service on a local level. In 2010, CLAPA obtained funding to employ a full-time Regional Coordinator to pilot localised services in the East of England for one year.

The main aims of the pilot project were as follows:

1. To increase branch and volunteer capacity
2. To provide face-to-face support for parents
3. To support children and young people to build social networks
4. To provide support for adults with a cleft
5. To raise awareness of CL±P amongst the general public
6. To provide training and support for non-cleft specialist Healthcare Professionals (HCPs)
7. To promote and support user involvement

The Centre for Appearance Research, based at the University of the West of England in Bristol, was asked to independently evaluate the success of the project during the pilot year.

The **key findings** of the evaluation are summarised below:

- The number of people actively volunteering for CLAPA in the region was significantly increased. Many of these volunteers completed formal training. Volunteers felt confident and supported in their role and were happy to be able to 'give something back' to those who had supported them.
- CLAPA formed important links with hard-to-reach communities, local schools, NHS cleft teams and a variety of different charities and organisations within the region and throughout the UK.
- Local parents, children, young people and adults affected by CL±P enjoyed attending a variety of social, fundraising and awareness-raising events and support groups.
- The opinions and needs of users of cleft services were used to guide the project and to inform the evaluation. Ongoing feedback has been collected and will be used to direct future projects.

A number of important **areas for development** were identified:

- Developing formal training for non-cleft specialist Healthcare Professionals, such as sonographers and midwives, in relation to the diagnosis and treatment of CL±P was identified as a priority for future work.
- A basic level of counselling/listening skills training is recommended for all CLAPA staff working with people affected by CL±P, so they can provide appropriate support.
- Ongoing development of the Cambridge Branch and other regional resources are encouraged. Local services could then be gradually expanded throughout the UK.

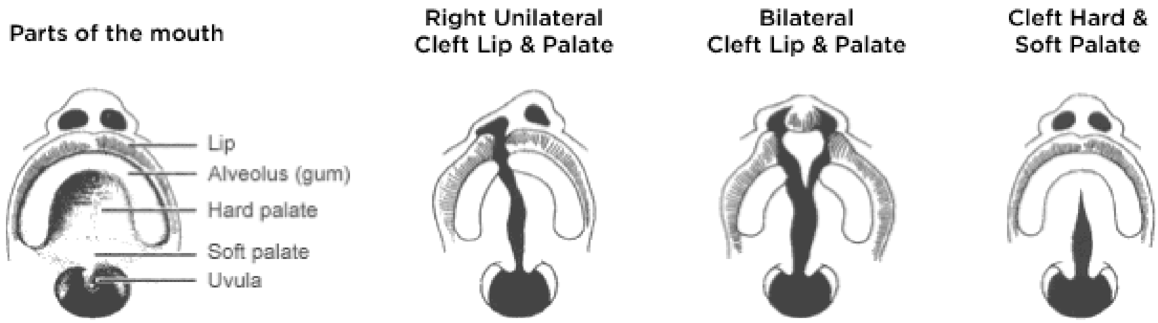
Thank you to everyone who contributed to the evaluation by participating in the May 2011 focus group, responding to the online survey, providing a case story, or writing a testimonial. Your views and support are much appreciated.

CLAPA Regional Coordinators Project Evaluation Interim Report

Appendices

Appendix 1 – Helpful terms

Cleft lip and/or palate (CL±P) – 'cleft' means 'split' or 'separation'. During early pregnancy separate areas of the face develop individually, and then join together. If some parts do not join properly this may result in a cleft, the type and severity of which can vary (see diagram below).



Parts of the mouth

Right Unilateral Cleft Lip & Palate

Bilateral Cleft Lip & Palate

Cleft Hard & Soft Palate

The Cleft Lip and Palate Association (CLAPA) - the only national charity in the UK dedicated to supporting all those affected by cleft lip and/or palate.

The Centre for Appearance Research – a centre of excellence for psychological and interdisciplinary research in appearance, disfigurement, body image and related studies.

Healthcare Professionals (HCPs) – general and specialist medical practitioners, nurses, dentists, allied health professionals and any other skilled workers providing a form of healthcare service.

Cleft.Net.East - a network based at Addenbrooke's Hospital providing a centre for excellence for the region's cleft lip and palate patients, offering care and support from birth right through to adulthood. It is a 'hub and spoke' service, where patients can be seen at Addenbrooke's (the 'hub') for surgery and special clinics, receiving part of their regular care, for example speech and language therapy, at more local centres ('spokes'). The core team travels to nine local hospitals for joint clinics with local specialists. The team is multidisciplinary, and is made up of plastic surgeons, speech and language therapists, orthodontists, ear nose and throat/audiology specialists, paediatricians, a psychologist and nurse specialists.

CLAPA Cambridge Branch – CLAPA has branches across the UK, primarily run by volunteers, offering local support to parents, patients and HCPs. Although often referred to as the Cambridge Branch, branch members live all over the region and offer support to all those affected by cleft in the East of England.

CLAPA Parent Contacts – trained volunteers who can offer personal knowledge of the difficulties that can be faced by new parents of babies born with a cleft lip and/or palate. Contact details for Parent Contacts are provided on the CLAPA website. Parents can get in touch directly, or can ask CLAPA to approach a Parent Contact on their behalf.

CLAPA Clinic Volunteer – trained volunteer CLAPA representatives attending cleft clinics in local hospitals to provide face-to-face support and information for parents and patients.

CLAPA Happy Faces groups – based around the region, these groups are run by trained Parent Contacts. Members meet on a monthly basis for the opportunity to gain "a sense of community, understanding, a place to laugh about the same things, talk about problems, and help each other."

CLAPA East of England Young People's group – a group for children and young people aged 11-16 years who were born with CL±P, and their families, to share experiences and enjoy evenings out together.

CLAPA Adult Council – a group of adults who were born with CL±P with the aim of taking an active part in shaping the future of cleft services.

CLAPA Children and Young People's Council – as above; aimed at children and young people.

User Involvement - research and/or service provision that is carried out 'with' or **'by'** members of the public rather than 'to', 'about' or 'for' them.

Appendix 2 – Executive summary of the Focus Group Report (May 2011)

Focus Group Report - Executive summary

As part of their already growing service, the Cleft Lip And Palate Association (CLAPA) recently launched their Regional Coordinators Project. This project has received funding from the Vocational Training Charitable Trust (VTCT) and will be piloted for 12 months in the East of England. In order to inform this pilot project, the Centre for Appearance Research (CAR) at the University of the West of England (UWE) was asked to assist CLAPA in facilitating and analysing a focus group session with parents of children affected by cleft. The aims of the focus group were to establish unmet need and to investigate what people want from local support.

Potential participants were approached via CLAPA during the Cambridge Branch Annual General Meeting, which also acted as a Launch Event for the Regional Coordinators Project, at the Frank Lee Centre on the Addenbrooke's Hospital site. Seven mothers and one grandmother participated. Also present was the Deputy CEO for CLAPA and the Lead Clinical Psychologist from the cleft team at Addenbrooke's Hospital. Of the participants' children, eight were born with a unilateral/bilateral cleft of the lip and/or palate. Additional reported complications included Pierre Robin Sequence, impaired hearing and glue ear. Four of the children were male; four were female. The children's ages ranged from four months to twelve years.

The hour-long semi-structured focus group discussion centred around which services participants currently access and what local services they would like to see improved or implemented. Data were professionally transcribed and analysed by researchers from CAR using inductive thematic analysis.

A number of **key messages** were evident:

- Support following diagnosis directly affects the pre- and post-natal experience
- Generic health care professionals and teachers need to have improved knowledge and understanding of the issues surrounding cleft. Communication and appropriate referral routes for specialist support and intervention also need to be enhanced.
- Psychosocial support should be available across the lifespan, rather than just focusing on the first one to two years, and is important for both the individual with the cleft and the parents
- Professional psychological input is particularly relevant during key transitional stages or 'milestones', which need to be more clearly identified
- Peer support is vital for adjustment and well-being

A summary of **participants' recommendations** is as follows:

- Continue to make feeding advice and equipment available in all clinics and via the CLAPA website
- Increase the availability of pre-natal 3D scans in routine care and improve knowledge and practice in the detection of cleft palate
- Improve training for generic health care professionals and teachers
- Identify the key players in the local area and support the coordination of cleft care to improve communication and the consistency of information given to families
- Increase collaboration with other charities and professional bodies
- Increase the psychosocial support available following the first two years after birth
- Implement basic training for CLAPA staff to provide additional psychological support and signposting
- Increase the number and quality of local support groups and social events for children and parents

Additional points for consideration included making a clearer distinction between CLAPA National and CLAPA Branches, particularly with regard to membership and the design of the websites. Participants also described the need to find better ways of inviting new families to join CLAPA and suggested the introduction of a local parent network to increase awareness and encourage volunteering and participation in meetings and events. The findings of this study will go on to inform and support CLAPA's Regional Coordinators Project, as well as cleft care on a broader scale.

Appendix 3 – Parent version of the online survey

CLAPA Regional Coordinators Project

PARENT version

Dear participant,

You are being asked to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being conducted and what it will involve. Please take the time to read the following information carefully. If anything is unclear, or if you have any questions, please contact Nicola (a researcher at the Centre for Appearance Research, University of the West of England): Nicola2.Stock@uwe.ac.uk

Who are the researchers?

The Cleft Lip and Palate Association (CLAPA) is the representative organisation for all people with and affected by cleft lip and/or palate in the UK. In February 2011, CLAPA appointed Claire Cunniffe as the Regional Coordinator for the East of England. Her aim over 12 months was to improve local support services for individuals affected by cleft and their families. The Centre for Appearance Research (CAR), a research centre based at the University of the West of England in Bristol, have been asked by CLAPA to evaluate how successful this pilot project has been.

CLAIRE CUNNIFFE
CLAPA East of England Regional Coordinator

NICOLA STOCK
Centre for Appearance Research

Why is the research taking place?

Having a physical appearance which is seen as different can have a profound impact on some people who are affected and their families. In addition, treatment can be difficult and ongoing. Despite this, many people cope very well with the demands upon them and succeed in minimising the impact on their lives. In order to encourage this success, it is vital that appropriate support be accessible.

Why am I being asked to take part?

You are being asked to take part because you represent many people with cleft and their families who have firsthand experience of what it is like to grow up with a cleft and of the support that is available.

Do I have to take part?

No, taking part in the study is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you are still free to withdraw at any time and without having to give a reason.

What will I have to do if I decide to take part?

You will be asked to complete a short online survey, to offer your views about how the CLAPA Regional Coordinator's role has affected the support that you and your family have received in the last year.

What are the possible benefits of taking part?

We hope that the comments you provide will help to improve support for people affected by a cleft and their families. You may also learn helpful information about support services that you were previously unaware of.

Will my information be kept confidential?

In strict accordance with the Data Protection Act (1998), full anonymity and confidentiality will be ensured at every stage of the research. Only the researchers working on this study will have access to your responses and all recorded information will be destroyed once the study is finished.

Who has reviewed the study?

This study has been reviewed and approved by the Faculty of Health and Life Sciences Ethics Committee at the University of the West of England and by CLAPA supervisory staff to ensure the research is being carried out in an appropriate manner.

Thank you for taking the time to read this information sheet. If you decide you would like to take part in this research study, please continue to the next page.

CONSENT FORM

Title of project: CLAPA Regional Coordinators Pilot Project: Final Evaluation

Name of researcher: Nicola Stock (Centre for Appearance Research, University of the West of England, Bristol)

☐ I confirm I have read and understood the information provided

☐ I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason

☐ I would like to take part in this study

Thank you for your interest in our survey. Please note that this survey is part of an evaluation of the CLAPA Regional Coordinators Project which has been piloted in the East of England. This survey is therefore only open to those who were living in the East of England region at any point between February 2011 and February 2012. The areas covered by the East of England Regional Coordinator are highlighted in the map below.

If this applies to you, please tick the box below to continue. If this does not apply to you, unfortunately you cannot complete the survey at this time.

○ I confirm that I was living in the East of England between February 2011 and February 2012

ABOUT YOU

Before you complete the survey, it would help us to know some information about you. Any information we collect will be kept confidential.

Are you:

○ Male

○ Female

What is your date of birth? (day/month/year) ☐

What is your home postcode? ☐

Please describe your ethnic origin:

○ White: British

○ White: Irish

○ Any other White background (please write below) ☐

○ Mixed: White and Black Caribbean

○ Mixed: White and Black African

○ Mixed: White and Asian
○ Any other Mixed background (please write below) ☐
○ Asian or Asian British: Indian
○ Asian or Asian British: Pakistani
○ Asian or Asian British: Bangladeshi
○ Any other Asian background (please write below) ☐
○ Black or Black British: Caribbean
○ Black or Black British: African
○ Any other Black background (please write below) ☐
○ Any other ethnic origin not listed here (please write below) ☐

ABOUT YOU continued...

Please tell us how many children you have:

○ 1
○ 2
○ 3
○ 4 or more

How many of your children were born with a cleft?

○ 1
○ 2
○ 3
○ 4 or more

Please write a number in the boxes below to tell us how many of your children have which type of cleft:

Unilateral cleft lip	☐
Bilateral cleft lip	☐
Unilateral cleft lip and palate	☐
Bilateral cleft lip and palate	☐
Cleft palate only	☐

Please write a number in the boxes below to tell us how old your children who were born with cleft are:

Under 3 years of age	☐
Aged between 4 and 11 years	☐
Aged between 12 and 17 years	☐

Aged 18 or older	☐

Please write a number in the boxes below to tell us how many of your children have received an additional diagnosis, or experienced any other problems relating to their cleft:

Pierre Robin Sequence	☐
22q11.2 deletion (e.g. DiGeorge Syndrome/Velo-cardio-facial syndrome/Shprintzen syndrome)	☐
Learning difficulties or a mental health condition (e.g. ADHD/Autism/Depression/Anxiety)	☐
Speech difficulties	☐
Problems with their teeth	☐
Hearing difficulties (e.g. hearing loss/glue ear/grommets	☐
Other (please tell us more)	☐

ABOUT YOU continued...

Were you born with a cleft yourself?

○ Yes

○ No

If yes, please tell us about the type of cleft you were born with:

○ Unilateral cleft lip

○ Bilateral cleft lip

○ Unilateral cleft lip and palate

○ Bilateral cleft lip and palate

○ Cleft palate only

Have you ever received an additional diagnosis, or experienced any other problems relating to your cleft?
(Please tick all that apply)

☐ None

☐ Pierre Robin Sequence

☐ 22q11.2 deletion (including DiGeorge Syndrome/Velo-cardio-facial syndrome/Shprintzen syndrome)

☐ Learning difficulties or a mental health condition (e.g. ADHD/Autism/Depression/Anxiety)

☐ Speech difficulties

☐ Problems with your teeth

☐ Hearing difficulties (including hearing loss/glue ear/grommets

☐ Other (please tell us more) ☐

Are you a member of the Cleft Lip and Palate Association (CLAPA)? (please tick all that apply)

☐ No

☐ Yes: I am a member of CLAPA National
☐ Yes: I am a member of a local CLAPA branch
☐ Don't know

YOUR SUPPORT

Thank you for telling us a little bit about you. We would now like to ask you questions specifically about the care your family receives for your child's cleft. None of the information you provide will go to your normal clinic/hospital, nor will it affect the care you receive either now or in the future.

Overall, are you happy with the **practical** support and information that your family receives from your local Cleft Clinic or Hospital?

○ Yes: All of the time
○ Yes: Most of the time
○ Sometimes
○ No: Not much of the time
○ No: None of the time

Please tell us how often you seek practical support or information for your child's cleft from the following sources (please tick all that apply):

	Never	Occasionally	Often	Don't know
My local doctor	○	○	○	○
A charity (please specify) ☐	○	○	○	○
A website (please specify) ☐	○	○	○	○
Friends	○	○	○	○
Family	○	○	○	○
My child's school	○	○	○	○
Other (please tell us more) ☐	○	○	○	○

On the whole, do you think you get enough practical support and information for your child's cleft?

○ Yes
○ No
○ Don't know

Overall, are you happy with the **emotional** support that your family receives from your local Cleft Clinic or Hospital?

○ Yes: All of the time

○ Yes: Most of the time

○ Sometimes

○ No: Not much of the time

○ No: None of the time

Please tell us how often you seek emotional support for your child's cleft from the following sources (please tick all that apply):

	Never	Occasionally	Often	Don't know
My local doctor	○	○	○	○
A charity (please specify)	○	○	○	○
A website (please specify)	○	○	○	○
Friends	○	○	○	○
Family	○	○	○	○
My child's school	○	○	○	○
Other (please tell us more)	○	○	○	○

On the whole, do you think you get enough emotional support for your child's cleft?

○ Yes

○ No

○ Don't know

If you would like to tell us more about the practical and/or emotional support you receive for your child's cleft please use the space below:

THE REGIONAL COORDINATOR

This last section is specifically about Claire (the CLAPA Regional Coordinator for the East of England). Claire began her post in February 2011, with the aim of improving local services for people affected by cleft and their families. We want to know how Claire's work has affected you in terms of the local care and support you have received for your child's cleft since she began her post.

Were you aware that a CLAPA Regional Coordinator had been employed in the East of England before you heard about this survey?

○ Yes
○ No
○ Don't know

Have you had any personal contact with Claire since she began her post?

○ Yes
○ No
○ Don't know

Was this contact (please tick all that apply):

☐ To discuss CLAPA membership
☐ To find out about the work CLAPA does
☐ For practical support or information
☐ For emotional support
☐ To volunteer for CLAPA
☐ Involving the organisation of a local social or fundraising event
☐ About raising awareness of cleft lip and/or palate
☐ To offer your views and ideas about cleft services
☐ Other (please specify) ☐

Overall, were you happy with the support you received from Claire?

○ Yes, definitely
○ Yes, fairly
○ Don't know
○ No, not very
○ No, not at all

THE REGIONAL COORDINATOR continued...

CLAPA BRANCHES AND VOLUNTEERING

Do you think the communication between your cleft team/hospital and your the local CLAPA branch is:

○ Very good
○ Good
○ Fair
○ Poor
○ Very poor
○ Don't know

Do you think the communication between the local CLAPA branch and the National CLAPA branch is:

○ Very good
○ Good
○ Fair
○ Poor
○ Very poor
○ Don't know

Do you think the communication between CLAPA and outside organisations (such as other charities, schools and so on) is:

○ Very good
○ Good
○ Fair
○ Poor
○ Very poor
○ Don't know

Do you think the communication between the healthcare professionals in the cleft team and the non-cleft specialist healthcare professionals is:

○ Very good
○ Good
○ Fair
○ Poor
○ Very poor
○ Don't know

THE REGIONAL COORDINATOR continued...

Have you ever volunteered for CLAPA?

○ Yes
○ No
○ Don't know

Would you be interested in volunteering for CLAPA in the future?

○ Yes
○ Maybe
○ No

○ Don't know

Which CLAPA volunteering activities have you been involved with? (please tick all that apply)

☐ I have been a Clinic Volunteer
☐ I am a member of the Adult Council
☐ I am a parent contact
☐ I have helped to raise awareness of cleft lip and palate/CLAPA
☐ I have been involved with local branch activities
☐ I have helped to organise social activities
☐ I have helped to raise money for CLAPA
☐ I have contributed to the CLAPA website
☐ Other (please specify) ☐

How long have you volunteered for CLAPA?

○ Less than 1 year
○ 1 - 2 years
○ 2 - 3 years
○ More than 3 years

Have you received any formal volunteer training from CLAPA since February 2011?

○ Yes
○ No
○ Don't know

How would you rate this training?

○ Very good
○ Good
○ Fair
○ Poor
○ Very poor
○ Don't know

Do you feel supported in your role as a volunteer?

○ Yes
○ Sometimes
○ No
○ Don't know

If you would like to tell us more about your experiences of being a CLAPA volunteer, please use the space below:

THE REGIONAL COORDINATOR continued...

EVENTS

Over the last year Claire has been involved in a number of different local events.

A list of these events is provided below. Please tick the boxes below to tell us which of these events you have attended (please tick all that apply):

☐ Fashion show (Towcester, April 2011)
☐ Cambridge Branch Annual General Meeting (Addenbrooke's Hospital, May 2011)
☐ Volunteer Induction Day (London, May 2011)
☐ Waendel Walk Fundraising Event (Wellingborough, May 2011)
☐ Annual Meeting of Towcester Town Council - fundraising cheque presentation (Towcester, May 2011)
☐ Peterborough Fundraising Event - head shaving (Peterborough, May 2011)
☐ Volunteer Induction Day (Corby, June 2011)
☐ East of England Young People's Group - Frankie and Benny's Restaurant (Bedford, June 2011)
☐ Cambridge Branch Summer Party (Cambridge, July 2011)
☐ Peterborough Happy Faces Group (Peterborough, August 2011)
☐ Charity Fun Day (Wellingborough, August 2011)
☐ East of England Young People's Group - Strikes Bowling (Ely, August 2011)
☐ CLAPA Conference (Manchester, September 2011)
☐ Silverstone Event (Silverstone, September 2011)
☐ Milton Keynes Happy Faces Group (Milton Keynes, September 2011)
☐ Asian Families Event (Luton, October 2011)
☐ The Cambridge Halloween Horror Ball (Cambridge, October 2011)
☐ Volunteer Induction Day (Peterborough, October 2011)
☐ Parent Contacts Training (Corby, October 2011)
☐ Parent Contacts Refresher Training (London, November 2011)
☐ Adult Council Meeting (Peterborough, December 2011)
☐ East of England Young People's Group - Laser Zone (Northampton, December 2011)
☐ Children and Young People's Council (London, December 2011)

On 11th December CLAPA will be hosting the 2011 Winter Wonderland Party in Cambridge (organised by the Cambridge branch). Are you likely to attend/did you attend this event?

○ Yes

○ Maybe

○ No

If you have been involved with any other CLAPA event between February 2011 and February 2012 please tell us more:

If you would like to tell us more about any of these events, please use the space below:

THE REGIONAL COORDINATOR continued...

SUPPORT FOR YOUNG PEOPLE

Are you or your child(ren) involved in any of the following support groups for young people with cleft (please tick all that apply)?

☐ Happy Faces support group (based in Peterborough)

☐ Happy Faces support group (based in Milton Keynes)

☐ East of England Young People's support group

Overall, how would you rate the support groups for young people with a cleft?

○ Very good

○ Good

○ Fair

○ Poor

○ Very poor

○ Don't know

Would you like a support group for young people with a cleft to be set up in your local area?

○ Yes

○ Maybe

○ No

○ Don't know

If you would like to share more of your thoughts on local support for young people with a cleft, please use the space below:

THE REGIONAL COORDINATOR continued...

Overall, how beneficial do you think it has been to have a CLAPA Regional Coordinator in your area?

- ○ Very beneficial
- ○ Quite beneficial
- ○ Somewhat beneficial
- ○ Not very beneficial
- ○ Not at all beneficial
- ○ Don't know

Would you like a CLAPA Regional Coordinator in your area more permanently?

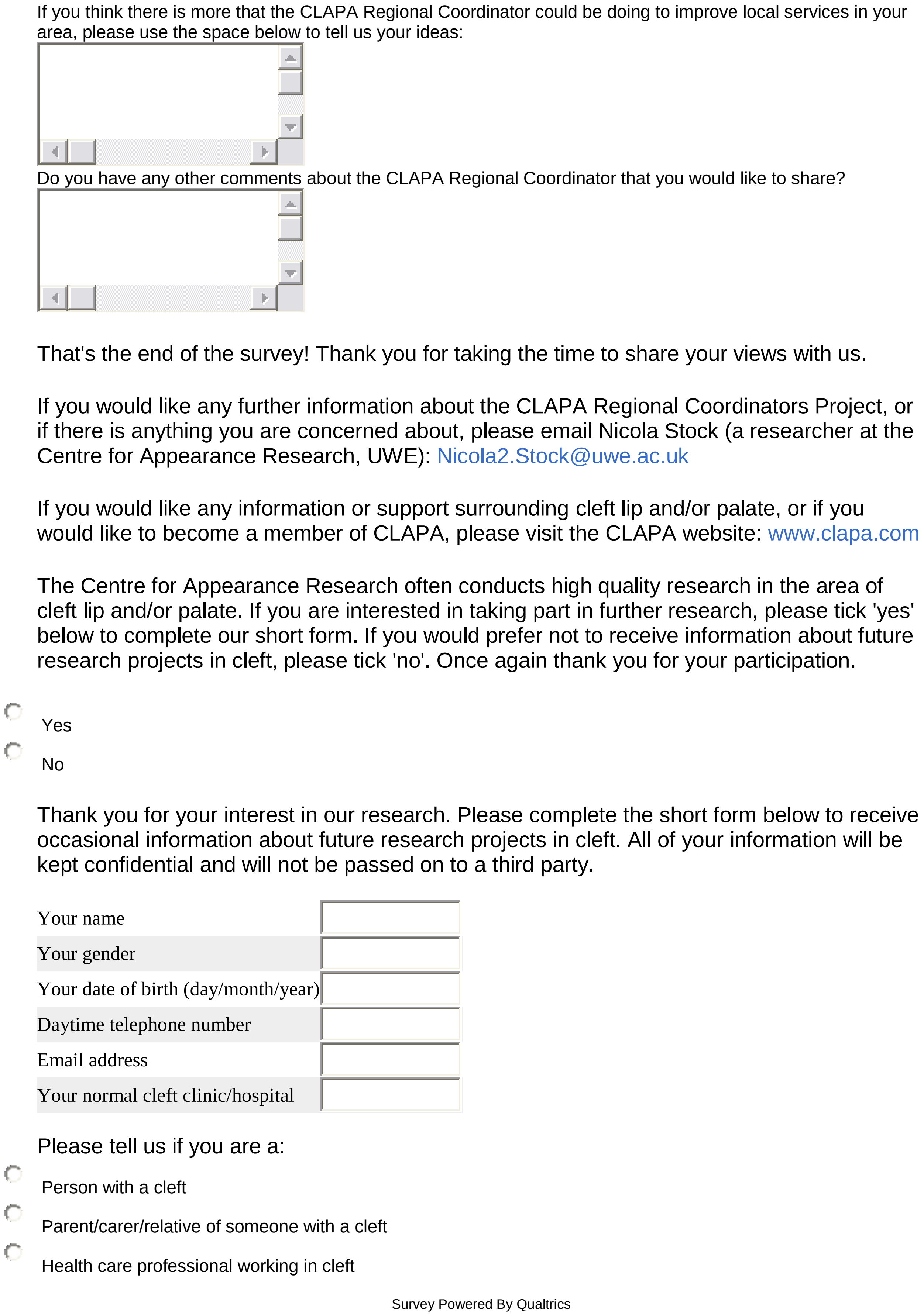
- ○ Yes
- ○ Maybe
- ○ No
- ○ Don't know

Do you think a CLAPA Regional Coordinator should be introduced in other regions in the UK?

- ○ Yes
- ○ Maybe
- ○ No
- ○ Don't know

Do you think the Regional Coordinator is someone who:

	Yes	No	Don't know
You can ask for practical support and information	○	○	○
Is friendly and approachable	○	○	○
You can ask for emotional support	○	○	○
Will help to represent your views to health care professionals and in research	○	○	○
Can raise awareness of cleft lip and/or palate	○	○	○



If you think there is more that the CLAPA Regional Coordinator could be doing to improve local services in your area, please use the space below to tell us your ideas:

Do you have any other comments about the CLAPA Regional Coordinator that you would like to share?

That's the end of the survey! Thank you for taking the time to share your views with us.

If you would like any further information about the CLAPA Regional Coordinators Project, or if there is anything you are concerned about, please email Nicola Stock (a researcher at the Centre for Appearance Research, UWE): Nicola2.Stock@uwe.ac.uk

If you would like any information or support surrounding cleft lip and/or palate, or if you would like to become a member of CLAPA, please visit the CLAPA website: www.clapa.com

The Centre for Appearance Research often conducts high quality research in the area of cleft lip and/or palate. If you are interested in taking part in further research, please tick 'yes' below to complete our short form. If you would prefer not to receive information about future research projects in cleft, please tick 'no'. Once again thank you for your participation.

○ Yes
○ No

Thank you for your interest in our research. Please complete the short form below to receive occasional information about future research projects in cleft. All of your information will be kept confidential and will not be passed on to a third party.

Your name	
Your gender	
Your date of birth (day/month/year)	
Daytime telephone number	
Email address	
Your normal cleft clinic/hospital	

Please tell us if you are a:

○ Person with a cleft
○ Parent/carer/relative of someone with a cleft
○ Health care professional working in cleft

Survey Powered By Qualtrics

Appendix 4: Example of a case story collected by the RC and shared on the CLAPA website.

Leah Mae

Up until my 20 week scan my pregnancy had been completely normal. As Leah was my first child, I was probably very naïve when I went to my 20 week scan as I was just excited about finding out the sex of my baby, I didn't really give much thought to any complications that could arise as my 12 week scan was fine.

When myself and my partner went in for the scan, the first sign of something not being quite right was when the lady said that the baby had her hand over her face and she couldn't see, she told us to go sit in the waiting room for ten minutes. She called us back through and started the scan again, she said that there was still a problem and that our baby "didn't have a top lip" (that was how she so sensitively put it!). After that we were ushered into a small side room and given a box of tissues and some leaflets. At this point I was sobbing and I can't really remember much apart from my partner saying "it's not that bad" and pointing to various pictures in these leaflets.

A couple of days later we were sent for a detailed scan in Nottingham, we met the Cleft Team and were given a lot more information and the opportunity to ask questions. On the detailed scan they could see that our baby had a unilateral cleft lip and palate that was quite wide. We were offered an amniocentesis as the risk of downs syndrome and other chromosome problems was slightly higher now that our baby had a cleft. But because my blood tests had come back at a very low chance of downs syndrome, we decided against having this done.

We then sat down with the Cleft Team and discussed all of our concerns. Having given so much thought to how my baby would look I hadn't really though about the practicality of it all e.g. how our baby would feed! We were shown the bottles and teats that we would most likely be using and told how we would need to squeeze the bottle gently as the baby sucked. It was also explained to us when and where the surgeries would likely take place. They also told us about other complications that cleft babies/children sometimes are affected by, she would need regular hearing tests as cleft children are prone to glue ear, she would probably need speech therapy or at least a speech therapy assessment and after her surgeries she would need regular clinic appointments.

We went away from this appointment feeling a little happier now we had a lot more information. But it was still a big shock for us both and I personally felt very guilty as if the cleft had been my fault and as if I had done something in my pregnancy to cause this. I later realised that there was probably nothing I could have done to prevent this from happening.

We had little involvement with the Cleft Team for the rest of the pregnancy, I did have some nurses come to show me how to express my breast milk when I was near the very end of my pregnancy and I froze some of this in preparation for Leah's birth.

On 23rd May 2009 at about 5am Leah Mae was born, I had no complications during labour and managed a natural birth, she weighed a healthy 7lb 3oz. Although she did look very different and her cleft was very wide she had beautiful big blue eyes and lovely wisps of fair hair, she was perfect to me.

LEFT: LEAH – A FEW DAYS OLD

As Leah was born at the weekend the Cleft Team didn't come out immediately so we used up the breast milk that I stored and then went onto formula feeding with a normal bottle and teat as my breast milk had dried up on the 3rd day. Although Leah did manage to feed with a normal bottle and teat for a few days, she couldn't have continued much longer as she was only getting very small amounts and was tiring easily from trying to suck very hard.

Once we were shown how to feed with the squeezy MAM bottles and had a go at it ourselves a few times, we were allowed home. Once at home we soon settled into a routine although feeding was not as simple as I thought it would be and Leah would take on board a lot of wind due to her cleft. We could sometimes be feeding and winding for a good hour and a half to two hours, then she'd sleep, then we'd have to do it all over again. It was very tiring, but I suppose all newborns are!

I was very apprehensive when I first had Leah and wasn't very comfortable taking her out and about for the first couple of weeks. When I finally plucked up the courage and started taking her out, the reactions were mixed if people saw her. Most people would simply just look and look away very quickly without saying anything, others would stare and some would come over and say things like "ahhh bless her, when is she going for surgery?" or "my cousin had a baby like that" or "my friend's little girl was born like that, you can't tell now". But after a few weeks I stopped seeing the cleft and just saw my little baby and I would wonder why people were staring, it was as if I had forgotten it was there.

On 15th September 2009, Leah was taken for her first surgery. The hardest thing was when the gas mask was held over her little face and she just went limp in my arms. She was down for about three hours and she had a lip adhesion and her hard palate repaired. She looked so different when she came round, her big wide smile had disappeared and her face was swollen, I cried when I saw her!

We really struggled after the surgery for a couple of weeks – she would not bottle feed at all. I think at first it was painful for her and then she became afraid of the bottle, we had to start feeding her in her sleep! We were allowed home after a week and then we struggled on. But after another week or so she picked up and we started weaning – which was much easier than bottle feeding.

After this we just got on with life as normal – Leah weaned well, she started nursery and settled in well and feeding her was no different from feeding a normal child – except we still had the squeezy bottle for night time feeding and other drinks. She still looked a little different as she only had a lip adhesion and this left her with what looked like a very slight cleft lip, but I was only asked about this a couple of times and both of those were by other small children.

On 6th July 2010, Leah went for her second surgery to repair her lip and her soft palate. This time she was in surgery for almost 5 hours, I was very worried!! Again she looked different but it wasn't as different as the first time around. We found this surgery much easier than the first one as Leah was actually able to eat! (although we did have to go back to pureed food!). We were soon allowed home and everything returned to normal.

LEFT: LEAH - 13 MONTHS OLD – A DAY AFTER SURGERY

Leah is almost 2 now and is a happy healthy little girl. She has regular check-ups and hearing tests and she is starting speech therapy soon, although she can say quite a few words. We still have surgery ahead as she will need her teeth sorting out when she is older but, for now, we can relax!

Although I was devastated when I first found out about the cleft, it hasn't been as hard as I thought, she is now like any other child and I wouldn't change her for the world!!!

LEFT: LEAH TODAY!

Appendix 5 – Summer Party 2011 Report (written by Claire Cunniffe)

CLAPA Cambridge Branch Summer Party 2011

Evaluation Report

August 2011

Introduction

CLAPA Cambridge held their annual Summer Party on Sunday 10th July 2011 at the Frank Lee Centre on the Addenbrooke's Hospital site in Cambridge. Prior to the event, 800 invitations were sent out to patients / parents from the database of the Cleft Team at Addenbrooke's Hospital. The event was attended by approximately 80 adults and 60 children from around the East of England region.

The Party ran from 1-4pm and included a BBQ, bouncy castle, face painting, a raffle, craft activities and clowns. The event was held in the Hexagon Hall of the Frank Lee Centre and the outside activities took place in a garden kindly provided by Bunnybrookes, a Kidsunlimited nursery.

Towards the end of the day, parents were encouraged to complete a short feedback form to share their experiences of the event. This brief report summarises their responses and also includes some personal feedback from the East of England Regional Coordinator's own experiences of the event.

Report Contributors:
Claire Cunniffe (CC), East of England Regional Coordinator, Cleft Lip and Palate Association (CLAPA)

Acknowledgements:
Many thanks to all those who completed evaluation forms on the day for providing valuable feedback on their experience at the Party. Thanks also to CLAPA Cambridge for allowing us to conduct this evaluation. Many thanks to Nicola Stock at CAR for her help and advice and to all staff at CLAPA for their continued support.

Design and Method

Families were greeted on arrival at the party and handed an Evaluation Form. The Evaluation Form had been designed specifically for the event with open ended questions to allow attendees to provide detailed comments and feedback. The questionnaires were designed to be anonymous but there was an option to provide a name and postcode if desired. The questionnaires were collected on the day and the resulting data was analysed by CC from CLAPA.

Methodological Considerations

An important aspect to consider when interpreting the information collected from these questionnaires is that a number of attendees are likely to have attended the event because they had attended, and enjoyed previous events and because they enjoy this type of social occasion. Whilst it is appropriate to involve this group because of the subject of the evaluation, it may not be fully representative of all those affected by cleft lip and/or palate.

It is also worth noting that, although a Feedback Form was given to each family who attend the event (approximately 40 - 50 families), only 16 completed forms were returned and therefore it may not be a full representation of the views of everyone attending the event.

Attendee Profile

It is estimated that approximately 80 adults and 60 children of varying ages, attended the Summer Party. One evaluation form was given to each family and a total of 16 forms were completed and returned. The particular demographics of those attending were not recorded.

Analysis and Results

The Evaluation Form explained that the feedback from the retuned forms would help CLAPA Cambridge to plan future events and that it may also help to access future funding. Participants were encouraged to expand on their answers using the back of the form if necessary. Participants' feedback and recommendations are detailed below.

Which Aspects of the day did you most enjoy?
Music and show
Seeing people from hospital that we'd not seen for ages and finding out how they were doing. Those that were in when we were.
Toys, activities for children, DJ, raffle
Dancing Stormtroopers, DJ and food.
Meeting other people who have been affected by cleft lip and/or palate.
Face painting, disco, BBQ, magic show.
Everything
Children's entertainment
The magician
Good all round – bouncy castle + play area great but also entertainment like clown and storm troopers.
The girls enjoyed everything especially the face painting.
Dancing
Seeing lots of happy children
Face paints, bouncy castle
Stormtroopers. Clown / show

The comments suggest that the range of entertainment and activities provided at the party were very popular and that families also valued the opportunity to meet with other families attending the event.

Which aspects did you least enjoy?
None x2 / nothing x2
The rain!! x4
The Stormtroopers x2 (scared our little girl)
Egg and Spoon race

The rain was the most unpopular aspect of the day. Some people said that there wasn't anything they didn't enjoy whilst several people didn't answer the question, which could be an indication that they enjoyed everything about the day. A couple of people did not enjoy the Stormtroopers as they scared their children.

What would you like to see more of?
Face painting / kids activities
Don't know, it's all really good.
Maybe more for the toddler age? Swings?
Just right! Maybe cleft team staff?
Soft play area.
Children's activities
Games for kids
More games
Well organised
Different hot food i.e. pizza or picnic
Variety of food

Most people seem happy with the range of activities provided but would like to see more of them, particularly for the younger age range. Two people commented on the food, indicating that there may be a need to broaden the range of food available on the day.

What would you like to see less of?
Don't know, it's all really good.
Rain x2, when you work out how to stop it, let me know.
Just right!
Maybe music slightly lower for those children who have just had grommets fitted.
Less Stormtroopers
Shorter show for kids
Nothing x2
Stormtroopers

The Stormtroopers were raised again by two people indicating that they could be a factor in discouraging people to attend in future. The comment regarding the music and the reason for it is also something to bear in mind in future as the volume of the music was quite high on the day.

What do you think you will remember most?
Face painting
Seeing our friends we don't get to meet due to distance.
Fun, son enjoyed himself.
Stormtroopers x4. People who raised money – tattoo!
The Rainbow Show
Children's Magic Show
Other children / families
Having faces, arms and legs painted!!!
Music and dancing, Stormtroopers
Meeting people

Again, the Stormtroopers are raised by 5 people, this time as their most memorable aspect of the day. This could be because they enjoyed them but the fact that they were memorable cannot be assumed to be for a positive reason. The entertainment in general seems to have proved popular with different people finding different aspects the most memorable.

Were there parts of the day that you think can be improved? If yes, please tell us your views.
Nope, had lots of everything, games, kids entertainment, it's all good.
Maybe some more for 1, 2, 3 years old? Was very well run.
No! x2
No – all good. (Brown sauce with burgers).
None
More games for the children
Nothing

Generally people seem happy with the day as a whole though again there appears to be a need to look at the entertainment provided for younger children and children in general.

Was there anything that you think could be included in the day in the future?
Nope, it's got lots of everything.
No! x2
Nothing

All responses were very positive with no recommendations other than to continue the good work.

Would you prefer the party to be held at the end of June / beginning of July or at the beginning of September or do you not mind?

September
June / July x8
Do not mind x5

Only one person opted for September, though 5 people were happy with any of the times of year suggested. The most popular appears to be the end of June / early July.

Would you be interested in coming to an Adults (aged 14+) Summer Evening Party?
Yes x5
No x5
Not really / Not sure / Not at the moment x5

There are at least 5 of the 16 people (31%) who completed the forms, who are interested in attending an Adults Summer Evening Party. If this is representative of the attendees as a whole, there is the potential for around 25 adults to attend an event. Of those who weren't interested or were not sure, two reported that the greatest barrier to attendance is childcare. It would therefore be worthwhile to think about the possibilities of organising childcare to coincide with the event to allow more adults to be able to attend. This could also be an opportunity to engage adults born with a cleft lip and/or palate who tend not to come to the parties which are aimed more at families.

Was the day too long, too short or just right?
Just right x14 (considering distance travelled to come).

Everybody that answered this question (15 out of 16) said that the length of the day was "just right".

Recommendations

The results from the questionnaire revealed a very positive view of the Summer Party. There is a clear need for the event and for the continuation of many aspects.

A summary of participants' recommendations is as follows:
- Continue to provide the activities and entertainment namely music / DJ, raffle, BBQ, face painting, bouncy castle, clown, storm troopers*
- Continue to provide opportunities to families to meet others who have been through a similar experience.
- The Stormtroopers* divide the attendees as some people love them and others hate them, as they scare their children. A discussion is needed at the next Branch meeting to decide whether to book them again for future parties.
- Organise additional activities / entertainment specifically for younger children and interactive activities such as games.
- Consider different options for food on the day including a picnic instead of a BBQ
- Hold next year's party at a similar time of year – late June / early July and keep the timings the same as this year.
- Consider organising an Adult's Summer Evening Party for 2012 and ensure that this is promoted to adults born with a cleft as well as parents of children born with a cleft.

Personal Feedback

The East of England Regional Coordinator also produced some personal feedback from the event. This feedback is detailed below:
- The set up for the day was a little chaotic as the volunteers were unsure what tasks needed to be done. There were enough people to help out but it seemed slightly disorganised as the volunteers hadn't been assigned tasks beforehand.
- Face painting had been advertised on the flyer for the event but a Face Painter had not been organised. Thankfully a CLAPA volunteer (who had never done Face Painting before) offered to help and this proved to be one of the most popular aspects of the day.

- The Bouncy Castle was delivered and there were specific instructions on the agreement which had to be adhered to. Some members of the committee were surprised by the instructions and were initially reluctant to adhere to them. The Branch have been hiring the Bouncy Castle from the same company for a number of years and the rules have not changed.
- The volunteers for the day generally stayed on the same duties throughout the day, including the more tedious tasks such as manning the bouncy castle.
- Despite all of the above comments, the event went very well and families appeared to enjoy themselves. The outside activities proved particularly popular despite the changeable weather and the relaxed and informal nature of the event seemed to allow families to mingle and talk to each other.

Recommendations

The personal feedback is mainly concerned with the organisation and set up of the event and highlights some areas for improvement:

- Prior to the event, duties should be assigned to members of the committee and other volunteers. This would particularly help new committee members and those who had volunteered their time specifically for this event. This delegation could take place at the Committee Meeting held in the run up to the event.
- Ensure that the flyer only details activities that are definitely going to be included on the day. If an element of the day such as Face Painting has not been confirmed, then this should not be specifically mentioned on the flyer as failure to deliver could lead to disappointment.
- If medium to high risk equipment such as Bouncy Castles are hired from an external organisation, then the guidelines from that organisation have to be strictly adhered to and this should be referred to in the Event Risk Assessment.
- At the Committee meeting held prior to the event, a rota should be drawn up to allow volunteers to move around the different tasks on the day. This rota should also allow for volunteers to have comfort breaks and must ensure that all areas are manned at all times.

Conclusion

The Summer Party was a great success with an overall positive response from the attendees who took the time to complete and return their feedback forms. The feedback form was a very useful tool to enable CLAPA and CLAPA Cambridge to assess the responses to the party, with overall positive feedback. The findings of this evaluation will go on to inform and support CLAPA Cambridge’s Winter Party and next year’s Summer Party.

The Personal Feedback highlights a need for the event preparation to be a little more thorough with some more attention to detail. All the recommendations are very easy to achieve without adding any additional workload onto committee members and volunteers and will make the event run more smoothly on the day.

Appendix 6 – Winter Party 2011 Report (written by Claire Cunniffe)

CLAPA Cambridge Branch Winter Party 2011

Evaluation Report

January 2012

Introduction

CLAPA Cambridge held their annual Winter Party on Sunday 11th December 2011 at the Frank Lee Centre on the Addenbrooke's Hospital site in Cambridge. Prior to the event, 944 invitations were sent out to patients / parents from the database of the Cleft Team at Addenbrooke's Hospital. The event was attended by approximately 90 adults and 80 children from around the East of England region.

The Party ran from 1-4pm and included a disco, Clown, Santa, craft activities and a raffle. The event was held in the Hexagon Hall of the Frank Lee Centre. On the day, parents were encouraged to complete a short Evaluation Form to share their experiences of the event. This brief report summarises their responses and also includes some personal feedback from the East of England Regional Coordinator's own experiences of the event.

Design and Method

Families were greeted on arrival at the party and handed an Evaluation Form. The Evaluation Form had been designed specifically for the event with open ended questions to allow attendees to provide detailed comments and feedback. The questionnaires were designed to be anonymous but there was an option to provide a name and postcode if desired. The questionnaires were collected on the day and the resulting data was analysed by CC from CLAPA.

Methodological Considerations

An important aspect to consider when interpreting the information collected from these questionnaires is that a number of attendees are likely to have attended the event because they had attended, and enjoyed previous events and because they enjoy this type of social occasion. Whilst it is appropriate to involve this group because of the subject of the evaluation, it may not be fully representative of all those affected by cleft lip and/or palate.

It is also worth noting that, although a Feedback Form was given to each family who attend the event (approximately 40 - 50 families), only 9 completed forms were returned and therefore it may not be a full representation of the views of everyone attending the event.

Attendee Profile

It is estimated that approximately 90 adults and 80 children of varying ages, attended the Winter Party. An evaluation form was given to each family and a total of 9 forms were completed and returned. The particular demographics of those attending were not recorded.

Analysis and Results

The Evaluation Form explained that the feedback from the retuned forms would help CLAPA Cambridge to plan future events and that it may also help to access future funding. Participants were encouraged to expand on their answers using the back of the form if necessary. Participants' feedback and recommendations are detailed below.

Which Aspects of the day did you most enjoy?

Clown, lots to do
All of it! Kids loved the clown, music, bubbles and Wii.
Disco and bubble machine

Clown – for K. Whole thing for me.
All of the day – clown, dancing and meeting Santa!
The craft section
Disco, bubble machine, Santa – everything really!
Everything, all brilliant.
Meeting other people, especially being able to tell them about A's experience to try to ease their minds about their baby's up and coming operation. Father Christmas and A loved the bubble machine!

The comments suggest that the range of entertainment and activities provided at the party were very popular and enjoyable.

Which aspects did you least enjoy?
Too hot!
Music a little loud!
The room was a bit hot and maybe a bit too dark.
Enjoyed everything.
Nothing, all good.
All good.
None

The only aspects of the day that those who completed the questionnaire did not enjoy were the heat of the venue (2 people), the loud music (1 person) and the darkness of the venue (1 person). These aspects are worth thinking about for future parties but as they were only commented on by a small number of people, they do not appear to be major issues for attendees in general.

What would you like to see more of?
Lights
Competitions like doughnut eating!
More dancing!
More things to make
Maybe more toys?
Already has a nice balance of entertainment
All good
Nothing

Most people seem happy with the range of activities provided but would like to see more of them, including more competitions (1 person), more dancing (1 person), more craft activities (1 person) and more toys (1 person). These should all be considered for the 2012 Winter Party.

What would you like to see less of?
Not always music on (frightening for little ones)
Nothing

The majority of people left this question blank, indicating that there was nothing they would like to see less of. Only one person commented that the music frightened young children.

Were there parts of the day that you think can be improved? If yes, please tell us your views.
Maybe have a buffet, rather than per plate cost
No x2
No – you're doing a brilliant job!
Nothing

Generally people seem happy with the day as a whole though one person commented that they would like to see a buffet in future, though it isn't clear from their comment whether or not they would be willing to pay for this.

Was there anything that you think could be included in the day in the future?
Making Christmas tree decorations
Lucky dip
Making reindeer dust
No
Nothing

The three suggestions for additional activities – making Christmas Tree Decorations, Lucky Dip and Making Reindeer Dust could all be considered for the 2012 Winter Party.

Was the day too long, too short or just right?
Just right x6

Everybody that answered this question (6 out of 9) said that the length of the day was "just right".

Other comments
Was a lovely day!
This was the first CLAPA event we've attended. Thoroughly enjoyed it and will definitely be attending more in the future. Thank you.

Recommendations

The results from the Evaluation Form reveal a very positive view of the Winter Party. There is a clear need for the continuation of the event.

A summary of participants' recommendations is as follows:
- Continue to provide the activities and entertainmen, namely the Clown, music, bubble machine, Wii, disco, Santa and the craft table.
- Continue to provide opportunities for families to meet others who have been through a similar experience.
- A discussion should be held at the party planning meeting as to whether the temperature of the room, the lighting and the volume of the music were at uncomfortable levels and whether or not any adjustments need to be made.
- Organise additional activities / entertainment including more competitions, dancing, toys, a Lucky Dip and craft activities such as making Christmas Tree Decorations and Making Reindeer Dust.
- Consider different options for food on the day such as a buffet at a cost per item instead of cost per plate.

Personal Feedback

The East of England Regional Coordinator also produced some personal feedback from the event. This feedback is detailed below:

- The set up for the day was greatly improved from the Summer Party with more Committee Members arriving early to help and people appeared clearer as to what tasks needed to be done.
- The music was quite loud and made it difficult hearing people speak when trying to register them as they arrived. People also seemed to arrive in fits and starts and therefore it would be helpful to have two, rather than just one person on the registration desk in the future.
- Most of the volunteers generally stayed on the same duties throughout the day but as the party was all contained inside within a small area, this did not seem to be a problem and there appeared to be enough volunteers to cover all the necessary roles and duties.
- The event went very well and families appeared to enjoy themselves.

Recommendations

The personal feedback is mainly concerned with the organisation and set up of the event and highlights that this has improved since the Summer Party.

The only suggested improvement would be to keep the level of the music lower during the first hour of the party to allow for registration and to allocate two volunteers to carry out this role.

Conclusion

The Winter Party was a great success with a very positive response from the attendees who took the time to complete and return their feedback forms. The feedback form was a very useful tool to enable CLAPA and CLAPA Cambridge to assess the responses to the party, with overall positive feedback. The findings of this evaluation will go on to inform and support future parties held by the Branch.

The Personal Feedback shows that lessons have been learnt from the Summer Party. The recommendations are very easy to achieve without adding any additional workload onto committee members and volunteers and will make the event run more smoothly on the day.

Appendix 7 – Example of articles published in the local press

Cambridge News

living

Helping you make the most of life

Style p22

Stepping out in beautiful boots

Food p20

WIN! tickets to Spirit of Christmas

Travel p44

Peak of perfection in Derbyshire

November 12, 2011

Lots to smile about!

Grins all round after baby Mia's successful first op to correct cleft lip and palate

Real Life

By Louise Martin

SAM Norman can't help but smile proudly as she talks about her five-month-old daughter Mia. "She's such a good girl," she beams, "and quite a determined little thing."

Just four weeks ago, Mia underwent a four-hour operation at Addenbrooke's to improve her cleft lip and palate, a condition she was born with.

It was at the 20-week scan that Sam, 33, and her husband James, 35, were told their first child had a cleft. "They picked it up on the scan and we didn't really understand what it was," she says. "The most I know about it was someone I went to school with had it. I thought it was quite a rare thing but I now know around one in 600 babies are born every year in the UK with a cleft lip or palate, or both."

As well as the cleft lip, later scans found that Mia also had a cleft palate. "We were hoping that it would just be the lip," remembers Sam.

"It was really upsetting. Obviously you want your baby to be fine and initially I thought 'what did I do wrong?', but I've been reassured there's nothing I could have done."

A cleft is a gap in the lip or mouth that arises in the early stages of pregnancy, when the face of a baby developing in the womb doesn't join up properly. It can affect just the mouth or palate or, like in Mia's case, both.

Although Sam is grateful they found out about Mia's condition before she was born, she admits it did have a negative effect on the pregnancy.

"I think the doctors have to prepare you for the worst," she says. "The pregnancy was nice, albeit, and I hate using this word, tarnished by all the worry of what was going to happen when she was born. I think you put yourself in a position where you can only expect the worst and then when she was born we were so delighted because it wasn't anything like we thought it was going to be."

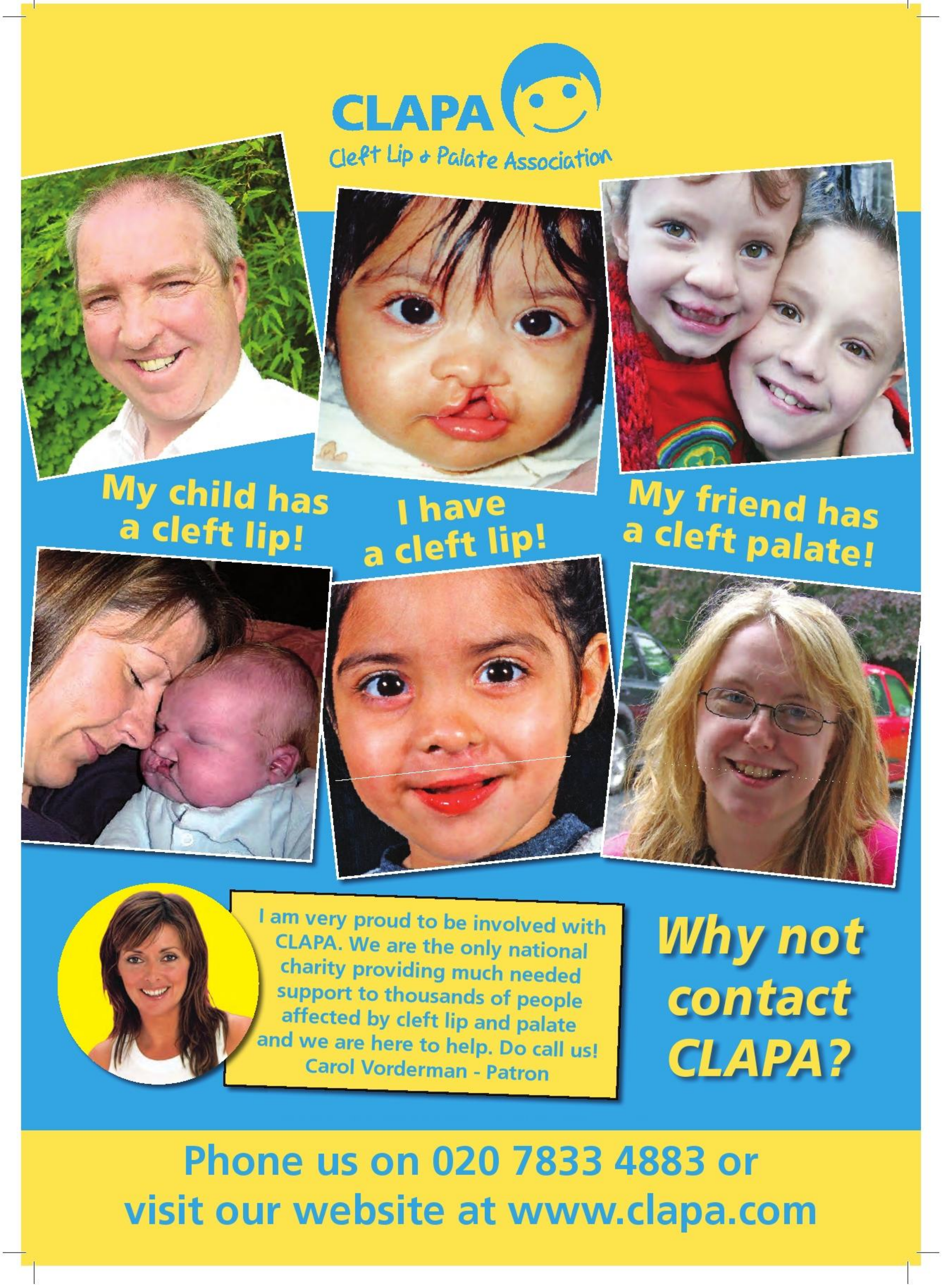
The couple were told Mia would need at least three operations to correct her clefts – one to improve her lip and now, a second on her palate, which she will undergo in January next year, and a third when she is nine or 10 years old.

■ continued on page 19

ALL SMILES: Mia and mum Sam today and, right, before the operation.

Main portrait by Keith Jones 782709

Appendix 8 – Awareness-raising poster



CLAPA
Cleft Lip & Palate Association

My child has a cleft lip!

I have a cleft lip!

My friend has a cleft palate!

I am very proud to be involved with CLAPA. We are the only national charity providing much needed support to thousands of people affected by cleft lip and palate and we are here to help. Do call us!
Carol Vorderman - Patron

Why not contact CLAPA?

Phone us on 020 7833 4883 or
visit our website at www.clapa.com

Appendix 9 – Example of a case study collected by the RC shortly after the project commenced

C is mum to M, aged 4, who was born with a full cleft palate and Pierre Robin Sequence and J, aged 13 who does not have a cleft. C and her family live in Ely and M is treated by Addenbrookes. C is a regular Face Forward user and member of the Cambridge branch. She works on Sundays so may not be able to make it to the Annual Meeting. C says that the Cleft team and the Cambridge branch are brilliant and has made some excellent suggestions for how CLAPA can best support local people.

Regular meetings

C thinks it would be good if, in addition to the parties that are held at Addenbrookes, there were some more meetings or coffee mornings in the area for parents to meet in a relaxed atmosphere as it is sometimes easier to chat to other parents and bring up issues away from the clinics. C feels that these should be solely for parents, not involving Cleft team staff and C would be interested in attending these meetings and potentially hosting them. A number of parents she has previously spoken to, have said that they do not attend Cambridge Branch Parties because they are held at Addenbrookes and their children associate Addenbrookes with treatment.

Coffee mornings

C has previously volunteered with the Cambridge branch to provide drinks and refreshments on clinic mornings to enable them to chat to parents. This always received a great response but the lack of space and time meant they were difficult to organise. To re-start the coffee mornings, it would be necessary to pull together a team of around 6 volunteers who would need to be registered as official Addenbrookes volunteers. At the moment, there are three volunteers – me, MN and C. JP, in Ramsey is a potential volunteer, as is MF – both of whom have been sent Volunteering Application Forms.

Parties

C says that the downside of the parties is that they always happen at Addenbrookes and the area covered is huge, so it makes it hard for people to travel e.g. from Norfolk. She suggested organising a "get together" in different areas, perhaps at a soft play centre away from the hospital. She thinks that this would be useful and if they are regularly advertised, she believes there would be a good turnout. A friend of C's, RF, in Sheffield, organises informal get-togethers where parents of children with clefts meet at a local museum or go for a meal. R is a Parent Contact and she is also a FaceForward user.

FaceForward

C has found FaceForward a fantastic resource as the other mums "just get" what she is talking about and they all become friends. However, to have similar contact face to face now and again would be wonderful. She also thinks that different people need help at different times.

Siblings

M being born with a cleft has had a knock on affect on her older sister, J. M's journey has been particularly difficult with numerous hospital visits (5 operations) and although C and her husband try very hard not to let it, this ultimately has an affect on family life and what her sister is able to do. C praised the events that CLAPA have previously organised for children and J was able to attend a couple of the Silverstone meetings when they happened a couple of years ago. However, C has suggested that it would be even better if something could be organised specifically for siblings. This would help even if was just once a year e.g. bowling/disco/pizza, etc as it would be nice for them to get some recognition, relax and talk to other children who understand, just like the parents need to do. J's friends sympathise with what she is going through (worrying about her younger sister) but they don't really understand and this is similar to how parents feel. J is very actively involved with CLAPA and even won the competition to name the character of Left Clip. J has previously suggested that CLAPA could set up forums on the children's websites specifically for siblings but this has never been taken forward.

Claire Cunniffe
March 2011

Appendix 10 – Testimonials

Testimonial 1 – parent of a child with CL±P

"I think Claire has been extremely beneficial for CLAPA. The number of local events and training sessions are testament to her hard work. Personally, if it wasn't for her encouragement and passion for the cause, I wouldn't have even considered volunteering to be a parent contact not alone become a clinic volunteer and set up the first regional Happy Faces group in Peterborough! Her enthusiasm for CLAPA is catching and her professionalism is uppermost but she is also a caring and sensitive individual. I am very grateful for all her time and support, and hope to continue to work with her in the future. Parents and families of cleft babies/children (like me) really value her work – it's for the good of our children that we raise awareness and offer support."

Testimonial 2 – parent of a child with CL±P

"I think Claire has done a wonderful job of increasing the number of volunteers in the region since she joined CLAPA. She is clearly very organised, dedicated to her job and conscientious. Claire is also very approachable and helpful. She is an asset to CLAPA and if CLAPA can recruit other Regional Coordinators like her to cover the whole country, I can see that both awareness of and support for those affected by clefts will increase."

Testimonial 3 – Trustee of the Tag Rugby Trust

"I have been working with Claire for the past few months and planning a programme with CLAPA that we hope can develop and grow. We are currently training at our cost, volunteers who are willing to develop Tag Rugby with Children and specifically developing a programme with Cleft kids. However we also wish to integrate the Cleft kids into mainstream events. Claire is great to work with and receptive to new ideas and working ways. I have enjoyed our meetings and training her – she is an asset to CLAPA and we will do all we can to help her role develop further."

Testimonial 4 – 13 year-old sibling of a child with CL±P

"Having a regional coordinator has been really good for me. New projects have been started and planned which hadn't been done before. It's also been nice because you have someone for your region to come and talk about CLAPA to your school if they are asked. Also if you have ideas about something you could maybe set up you can contact them easily. I think having a regional coordinator has been really good!"

Testimonial 5 – member of the Adult Council

"The Adult Council is a diverse group of adults from around the country, who all have their own experience of CLAPA and their own reasons for getting involved. We have only been meeting together for a year and a half and initially it took some adjusting to find out where we fitted in the CLAPA structure of branches and head office staff. As soon as Claire came to one of our meetings in December, it felt as though the Adult Council had completely slotted in to place. It was helpful to have a central figure who could liaise between head office and us. Her role has opened up opportunities around the country like meeting with parents and attending training days. Having a regional coordinator has enabled us to take part in smaller events which may not have been made known to us. She is the perfect link between CLAPA head office and the people who need our help.

While our roles are voluntary – we all have jobs outside of our Adult Council roles – Claire's is a permanent post and she is out communicating with the people we want to help every day. She can offer us valuable feedback that we would not be able to glean for ourselves."

Testimonial 6 – member of the Adult Council
"The CLAPA Adult Council is a group of adult CLAPA members with clefts whose role within CLAPA is to represent the wider adult membership. We have found that CLAPA's first regional coordinator in East of England, Claire Cunniffe, has been able to unlock a level of local contact that would have been far more difficult for CLAPA to achieve at a Head Office level, or for volunteers to achieve with limited time availability. Crucially, Claire has the three things that regional coordinators need – time, understanding and skill. Having a network of Regional Coordinators across the UK would be invaluable to CLAPA's future work, as they would be able to support the work of branches and voluntary councils in providing a more local presence and communicating at a more local level, understanding members' needs and providing more bespoke support. Without this, contact will remain more generalised, with impact lessened as a result."

Appendix 11 – The East of England Regional Coordinator's Personal Reflection of the pilot year

East of England Regional Coordinators Pilot Project
February 2011 – January 2012
Personal Reflection (CC)

I applied for the position of East of England Regional Coordinator with the Cleft Lip and Palate Association (CLAPA) after taking voluntary redundancy from my role as Community Manager at Warwickshire Wildlife Trust (WKWT).

I started in post on 1st February 2011 and my initial aim was to ensure I was able to represent the organisation and its beneficiaries effectively. I wanted to establish the type of local support that people affected by cleft in the region wanted and needed. Having not been directly affected by cleft myself; I was keen not to make assumptions about the type of support that people would most benefit from.

In the first month, I made contact with the existing stakeholders in the region, including CLAPA Cambridge, the local Cleft Team and the existing Parent Contacts. I publicised my role through the CLAPA e-newsletter, website and social networking sites. I also emailed everyone in the region who had completed the CLAPA 2010 survey and had agreed to be contacted again and had an excellent response. I followed up these responses with phone calls and personal visits, during which I interviewed people to find out what local support they would like to receive.

As a result of the feedback I received, I knew that local support was needed and that people were keen for opportunities to meet up with others affected by cleft on a regular basis. Some parents expressed an interest in establishing their own local group.

I have really enjoyed developing the role, in particular meeting the adults and children with clefts and their families and training volunteers and it has been particularly inspiring to see the new groups develop. I think it is important for CLAPA to have a member of staff based locally as the face-to-face contact makes such a difference in building up relationships with local people. Being based in the region has enabled me to get to know some of the volunteers really well, to attend clinics at the hospitals and build up good relationships with the local Cleft Team.

I have learned a lot since working for CLAPA, including knowledge of clefting and the associated issues. I have also learnt a lot about people's personal experiences. I feel confident that I have enough knowledge to talk in public about clefts and educate people about the issues faced by someone affected by cleft.

CLAPA now has several active volunteers in the region and beyond, 8 new Parent Contacts and numerous active local groups, all as a result of the project. I have been extremely impressed by the number of people who wish to volunteer because of their personal experiences of cleft and the enthusiasm and dedication these volunteers have.

The last 12 months have not been easy and there have been challenges to face. One of the main challenges has been working with the local Branch who have delivered support to local people without the support of a paid member of staff, for several years. It has been necessary to instigate some changes in the way the Branch work and these changes have not all been well received. The previous Branch Chairman has taken the decision to resign and the relationship with the Branch became increasingly difficult. However, the Branch have recently recruited a new Acting Chairman and the future is looking more positive.

My aim now is to secure funding, initially for 3 Regional Coordinators, and eventually for CLAPA to be able to employ 9 Regional Coordinators across the UK. I am also keen to ensure that the volunteers, who have already been recruited and trained over the last 12 months, are properly supported as they are key to enabling CLAPA to support people affected by cleft at a local level. It is vital that volunteers are effectively managed, supported and motivated in order for them to be able to deliver their roles effectively and for them to feel valued. Feedback from a survey of existing Parent Contacts in June 2008 showed that the nearly 70% of those who responded to the survey still felt equipped to deal with enquiries, but 93% expressed an interest in attending a Refresher Training Day.

If we secure funding for the initial 3 Regional Coordinators, I will be keen to share my knowledge and experience with the 3 new members of staff. However, I will also allow them to develop work in their areas in their own way and recognise that issues may vary from one region to the next. Having managed a team of 11 staff in my previous organisation, I feel confident about managing staff in addition to volunteers. However, as all staff will be home-based, and in different regions, I will be very keen to encourage regular communication and physical meetings to share ideas, experiences and good practice.

I look forward to what I see as a very exciting future for CLAPA.

Claire Cunniffe
East of England Regional Coordinator
January 2012

Centre for Appearance Research, University of the West of England, Bristol: March 2012