



CLAPA Regional Coordinators Project

Evaluation Interim Report

End of Year Four

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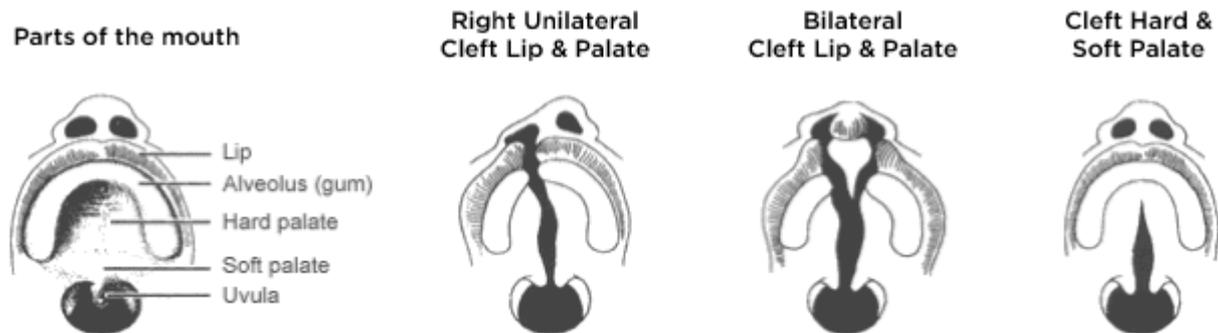
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Glossary of terms

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).



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.

Regional Coordinator – a member of CLAPA staff who is based in a particular region and is responsible for increasing the diversity and frequency of local activity within that region.

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

NHS cleft team – cleft treatment is offered as part of the National Health Service (NHS) and is provided by a multidisciplinary cleft team, offering specialist treatment and support to affected individuals and their families from birth through to adulthood. Cleft teams usually involve Cleft Nurse Specialists, Plastic and Maxillofacial Surgeons, Speech and Language Therapists, Orthodontists, ENT (ear, nose and throat)/Audiology Specialists, Paediatricians, and Psychologists. There are 17 cleft teams in the UK.

Cleft.Net.East - this network provides treatment for all cleft lip and palate patients in the East of England, and is based at Addenbrooke's Hospital (Cambridge).

West Midlands Cleft Service – this service covers all patients living in the west of the Central Region and is based at the Birmingham Children's Hospital.

Trent Cleft Service – this service covers all patients living in the east of the Central region and is based at Nottingham Children's Hospital.

North Thames Cleft Service – this service covers parts of the South East region and is based across two surgical sites; Great Ormond Street Hospital (London) and Broomfield Hospital (Chelmsford).

South Thames Cleft Service – this service covers parts of the South East region and is based at Guy's and St Thomas' Hospital (London).

Spires Cleft Service – this service covers parts of the South East region and is based across two surgical sites; Salisbury District Hospital (Wiltshire) and John Radcliffe Hospital (Oxford).

CLAPA Branch – CLAPA has branches across the UK, primarily run by volunteers, offering local support to parents, patients and HCPs.

CLAPA Parent Contacts – trained volunteers who can offer personal knowledge of the difficulties that can be faced by new parents of babies born with CL/P. 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 Peer Contacts – Peer Contacts are trained volunteers who were born with a cleft themselves. This is a new initiative by CLAPA but will follow similar protocols as Parent Contacts.

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 informal groups are run by trained Parent Contacts. Members meet on a regular basis for the opportunity to gain “a sense of community, understanding, talk about problems, and help each other.”

CLAPA Adult Voices 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 aged 9-17.

Patient and Public Involvement (PPI) - research and/or service provision that is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE). Patient representatives play an active role in shaping the services they benefit from.

Patient Voice Project – a project aimed at increasing PPI within research and cleft service delivery.

CLAPA Regional Coordinators Project - Evaluation Interim Report (End of Year Four, Oct 2016)

Lay 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 throughout the lifespan, 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. Following the success of the 2010 pilot project, the Cleft Lip and Palate Association (CLAPA) obtained funding from the Big Lottery Fund to employ three Regional Coordinators (East of England, East and West Midlands (known as Central), South East) over four years, with the aim of improving local service provision for families, young people and adults affected by CL/P.

The three core outcomes for this project are as follows:

Outcome 1: Volunteers demonstrate useful and transferable new skills, feel more confident and better able to support others affected by cleft.

Outcome 2: Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental wellbeing, enabling to live fuller lives in which having a cleft is not an issue.

Outcome 3: Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.

The Centre for Appearance Research, based at the University of the West of England in Bristol, was commissioned to conduct an independent evaluation of the project, allowing service users to provide feedback and to supply evidence to current and future funders to support the continuation of existing services and the development of new services and activities.

The 'End of Year Four' report (Dec 2015 - Oct 2016) demonstrates that the RC Project has continued to grow steadily throughout the year, delivering a service that individuals and families affected by cleft value. In addition, the project is highly commended by Health Professionals. Evaluation data collection is stronger in some areas than others, with feedback from adults born with cleft being the most limited. Going forward, this is the area that requires further support and development. The Residential Weekends continue to be a great success. Going forward, it may be beneficial to host more events aimed at children aged 11 years and above. It is recommended for the RCs to continue to offer volunteer training in both group and one-to-one formats on a 'best-fit' basis. Finally, RCs should continue to utilise creative and novel advertising and marketing approaches to promote events, in the hope of attracting more attendees.

A huge thank you to everyone who contributed to the evaluation report. For more information about the Regional Coordinators project, please contact Claire.Cunniffe@clapa.com.

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 for most individuals the treatment pathway ends when they reach the age of 18 years, CL/P is often considered to be a lifelong condition. Some individuals may continue to experience difficulties into adulthood, and different life stages are likely to bring new challenges. Unfortunately, little is known about what happens to adults once they leave the service. Access to appropriate support is vital to encourage psychosocial adjustment and ultimately improve outcomes for parents, children, young people and adults with CL/P.

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 Health Professionals (HPs) 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 strategic review, CLAPA conducted a National survey open to anyone with an interest 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 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. This project was piloted in 2011-2012 in the East of England and was evaluated by the Centre for Appearance Research (CAR) at the University of the West of England (UWE). With the support of this evaluation report, CLAPA was able to gain further funding from the Big Lottery Fund to employ three Regional Coordinators (East of England, East and West Midlands (known as Central) and South East), using a staggered approach over four years.

Project Outcomes

The CLAPA Regional Coordinators Project has three key outcomes, which CAR is independently evaluating:

Outcome 1: Volunteers demonstrate useful and transferable new skills, feel more confident and better able to support others affected by cleft.

Outcome 2: Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental wellbeing, enabling to live fuller lives in which having a cleft is not an issue.

Outcome 3: Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.

All evidence obtained during this project will be evaluated against these three key outcomes.

This report

This report describes the findings obtained from the evaluation during Year Four. Previous reports have been provided for the pilot year, for the End of Year One, End of Year Two, and for the End of Year Three. This report accompanies the 'End of Project' report.

Year Four has seen an expansion in activity across all regions (East, Central, and South East). Data has predominantly been collected using the measures provided by CAR, as well as other methods where appropriate. This data is presented throughout this report according to each region, and in relation to each of the three key outcomes, along with summaries and future recommendations. Supplementary documentation, where relevant, is provided within the Appendices of this report.

East of England region

The East of England region is defined as: Bedfordshire, Cambridgeshire, Essex, Norfolk, Northamptonshire, Suffolk, parts of Hertfordshire and parts of Lincolnshire. Hamza Anwar has been in post as the East of England Regional Coordinator since April 2016. Previous to that, Tansy Miller was the RC for this region from December 2013 and has therefore also contributed to this report.

Outcome 1 (East of England)

“Volunteers demonstrate useful and transferrable new skills, feel more confident and better able to deliver support to others affected by cleft.”

Overview

The Regional Coordinator (RC) for the East of England has trained several volunteers, including existing volunteers and volunteers who are new to CLAPA. Feedback was collected from training conducted using a group format, and from training conducted on a one-to-one basis, a format originally introduced in Year Three of the project.

Feedback from new volunteers

The RC obtained feedback from 14 new volunteers. These new volunteers gave the following reasons for attending a training day (in order of most frequently reported):

- To learn more about CLAPA
- To find out how to help others
- To learn more about cleft
- To meet other individuals and families
- To give something back
- To meet health professionals
- To learn more about the structure of CLAPA

At the end of the training all 14 new volunteers reported that their reasons for attending were met. In addition, these new volunteers reported the aspects that they most enjoyed from the induction training:

- Meeting the Regional co-ordinator
- The new one-to-one format
- Getting to know others who are affected by cleft in some way
- Learning more about how to support my son in the coming years
- Learning more about how it affects children as they get older
- Discussions about older adults who have had clefts and the psychology of their journeys
- The activities (e.g., icebreaker quiz) were highly enjoyable and interactive
- Group discussions
- Information on how to get involved with CLAPA
- The informal atmosphere made the day comfortable and enjoyable
- The smaller size of the group made everyone's story/queries voiced and well responded to

As a direct result of the training, nearly all (12/14) new volunteers reported having access to a local support network. The majority (11/14) reported that they now felt more able to support others affected by cleft, while nearly all (13/14) felt they had gathered information that will help them to address cleft-related issues in a positive way. In addition, most (4/5¹) feel more confident in connecting with people for support with cleft challenges, feel part of a community of people affected by cleft, and report having increased confidence in supporting their child with a cleft (3/5¹, where applicable). All new volunteers reported that they would attend this or similar events in the future, and most (4/5¹) reported the acquisition of useful and transferable new skills as a direct result of attending the training.

Feedback from existing volunteers

Existing volunteers have continued to be active over the course of Year Four, facilitating a variety of activities and events with support and guidance from the RC. Existing volunteers were asked to feed back on the specific roles they have been involved with over the course of this year. Nearly all of the existing volunteers from whom feedback was obtained reported being a Parent Contact (5/6). All reported involvement in fundraising and awareness raising (6/6). The majority (4/6) fed back that they had been involved in establishing a Happy Faces group. A minority of existing volunteers reported being involved in establishing a group for adults with cleft (2/6), part of a branch committee (2/6), and involved in children and young people (CYP) services (1/6), respectively.

Existing volunteers indicated that they predominantly felt happy (4/6), confident (5/6), and supported (4/6) in their role. In addition, all or nearly all reported that they felt that they were achieving their aims as a volunteer (5/6), were more able to support others affected by cleft (6/6), and had greater confidence in supporting their child born with a cleft (5/6) as a result of their involvement with the RC Project. All existing volunteers fed back that they had gathered new knowledge and information to help them cope with cleft-related challenges (6/6), while most reported developing useful and transferable new skills (4/6). All existing volunteers (6/6) from whom feedback was obtained reported having greater access to a local support network, knowing more people affected by cleft, feeling more confident in connecting with others for support with cleft-related challenges, and feeling part of a community of people affected by cleft, as a direct result of their involvement with the RC Project. Existing volunteers reported that meeting new parents and children, and helping to give back to the cleft community, were aspects they enjoyed most about their role.

One existing volunteer fed back the following:

“The RC has always been supportive and very helpful to me as a volunteer and Parent Contact. I think if it wasn’t for the RC I would have given up my volunteering months ago.”

Outcome 1: Summary (East of England)

The RC has recruited and trained new volunteers, while also maintaining a good relationship with existing volunteers. Overall, the feedback obtained from both groups of volunteers is very positive.

¹ Not all new volunteers were asked these questions because different evaluation forms were handed out

The one-to-one training format, which was introduced in Year Three, continued to be appreciated in Year Four, evidenced by comments on the feedback forms, for example, “enjoyed the personalised/individualised nature”. However, one-to-one training appeared to have a knock-on effect on trainees’ perceived accessibility to the wider community. Thus, it is recommended that CLAPA continue to provide both training options on a ‘best-fit’ basis (e.g. the nature of training, the volunteer’s location, and the needs and preferences of the volunteer), as well as for this to be monitored accordingly.

The RC has collected a good amount of volunteer feedback given his length of time in post. One point for consideration is the type of evaluation form distributed. In some cases, the incorrect forms and/or old versions of forms were used, resulting in data that was suboptimal.

Although the majority of existing volunteers reported being happy, confident and supported in their role, a minority of volunteers reported less favourable outcomes, which would be worth following up with the aim of finding solutions.

Outcome 1: Key recommendations (East of England)

- Continue to recruit, train and support volunteers across the region.
- Continue to offer one-to-one and group training sessions on a ‘best-fit’ basis.
- Continue to engage with all volunteers on a regular basis and incorporate their feedback into service delivery.
- Continue to expand CLAPA’s presence in the region and encourage more people to run and attend local training days and events.
- Endeavour to bring volunteers together, particularly those in more remote areas where the potential for volunteers to feel isolated is higher.
- Continue to nourish relationships with local NHS cleft teams and expand this knowledge to working with other relevant organisations where beneficial.
- Continue to raise awareness of CL/P and of the volunteering opportunities that CLAPA provides within the region.

Outcome 2 (East of England)

“Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental health and wellbeing, enabling them to live fuller lives in which having a cleft is not an issue.”

Overview

The RC has delivered several events aimed at children and young people, including a family day and a Christmas party. In addition, the RC has collected parent-reported feedback relating to children and young people from Happy Faces group meetings. Some feedback from adults born with a cleft, who are also volunteers was collected.

Feedback from children, young people and adults

Parent-reported data on children was collected from 16 families from a family day held in Thetford. Parents reported that the majority of children (10/16) enjoyed the event. Some parents provided additional comments on the event, including (for example):

“A fun day for the children”

“A great event”

“We had a wonderful time”

Some photographs from the Thetford Family Day are included below:



Parent-reported data on children was similarly obtained from a Christmas party held in the region, with all those who provided feedback reporting that their child(ren) enjoyed the event. Parents also provided the following feedback when asked what positive (or negative) affects the event had on their son/daughter:

“It showed her that there are other children just like her.”

“My daughters were able to socialise with other children that have gone through the same and have the situation normalised for them.”

The following feedback was obtained from a new member of the CLAPA Children and Young People's Council after attending their first meeting:

“I really enjoyed the meeting, it was so nice meeting everyone and everyone was so welcoming and friendly. Everyone was so lovely and easy to get along with – I couldn't have asked for a better day! I'm excited to see what the other meetings bring”

Data was collected from some parents that attended the Happy Faces group meetings in Norfolk and Suffolk and all reported that their son/daughter would attend further meetings again.

A small amount of data was collected from adults born with cleft who were also volunteers. The majority of this group of adults reported that, as a direct result of their involvement with the RC Project, they have access to a local support network (10/12) and have learned new ways of coping with cleft-related issues in a positive way (11/12).

Outcome 2 – Summary (East of England)

The RC has supported the running of events around the region for children and young people. Although feedback was provided by their parents, this feedback was very positive. Substantially less events have been run for, and data collected from, adults born with CL/P. The small amount of feedback gained from adults, is however positive.

Outcome 2 – Key recommendations (East of England)

- Continue to host events for children and young people of all ages across the region (and encourage volunteers to do to same), collecting as much data as is possible.
- Increase efforts to engage adults with cleft in regional activities and endeavour to collect evidence of this impact.
- Continue to raise the profile of events such as these in order to attract more participants.
- Continue to partner with other charitable organisations to increase the scope of these events and to build upon relationships.
- Continue to support the CYP and Adult Voices Councils, including joint meetings where appropriate.

Outcome 3 (East of England)

“Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.”

Overview

Family events have been held in the region from which feedback has been collected from parents/guardians, including a Family day, a Christmas party, and Happy Faces group meetings.

Feedback from parents/guardians

Data was collected from 16 parents, 11 of whom were new to CLAPA events. Parents gave the following reasons for attending (in order of most frequently reported):

- Meeting other individuals and families
- To learn more about cleft

- To learn more about CLAPA
- To find out how to help others
- To give back to cleft services

When asked which aspects they most enjoyed, the parents/guardians responded with the following:

- Meeting other families
- All of it!
- The activities

The parents/guardians responded with the following when asked what could be improved:

- Marketing and advertising for events
- The event was split inside and outside, it would be better if it was all in one place

As a direct result of attending the Family Day, the majority of parents/guardians reported having access to a local support network (15/16), feeling part of a community (14/16), and knowing more people affected by cleft (15/16). In addition, most reported feeling more confident in connecting with others for support (11/16), feeling more able to support other families and individuals affected by cleft (12/16), and having increased confidence in supporting their own child (10/16). Most of the parents/guardians also reported that they had gathered new knowledge and information to help them cope with cleft-related issues in a positive way (14/16), as a result of attending the family day. Finally, most indicated that they would attend another regional event in the future (14/16).

Ten parents/guardians attended a Christmas party held in the region, one of whom was new to CLAPA events. Parents/guardians gave the following responses when asked about their reason(s) for attending (in order of most frequently reported):

- To meet other families
- To learn more about CLAPA
- To find out how to help others affected by cleft
- To meet health professionals
- To learn more about cleft

When asked which aspects they enjoyed the most, the parents/guardians responded with the following:

- Watching the kids have fun
- Finding out about other parent contacts
- Meeting with others/other parents
- Hearing others' stories

Parents/guardians responded with the following when asked what if anything could be improved:

- Continue as are, but maybe add an element of optional fundraising so that guests feel like they are giving back to CLAPA

As a direct result of attending the Christmas party most of the parents/guardians reported having access to a local support network (9/10), that they were more able to support others affected by cleft (8/10), and

that they had gathered information to address cleft issues in a positive way (8/10). All of the parents/guardians from whom feedback was gained reported that they would attend a regional event again (10/10).

Two families (2 parents, 3 children altogether) attended and provided feedback for Happy Faces group meetings in Norfolk and Suffolk. They had all attended CLAPA events before. The parents gave the following reasons for attending (in order of most frequently reported):

- To meet other families
- To learn more about cleft
- To learn more about CLAPA
- To find out how I can help others

Both parents reported that meeting and talking with other parents was the part they most enjoyed. The aspects they felt could be improved included the travelling distance required to attend. Both parents responded that they have access to a local support network, know more people affected by cleft, and feel part of a community as a result of attending the Happy Faces groups. In addition, both reported feeling more confident in connecting with other people for support with cleft-related challenges, feeling more able to support others, and having increased confidence in supporting their own child born with cleft. One parent reported that they had gathered new knowledge and information to help cope with cleft-related challenges, while the other reported no difference. Similarly, one parent reported that they would attend again, whilst the other wasn't too sure whether they would.

Outcome 3 – Summary (East of England)

The RC has supported a number of events for families affected by cleft in the region, which have predominantly been rated favourably by attendees. Of the minority who did not give such positive responses, reports were more 'neutral' in nature, which may be related to the nature and purpose of the event. In one case, for example, the Family Day was not specifically targeting issues such as parents' confidence to support their own child, but rather aimed to provide a platform for families affected by cleft to get together. A recurring point evidenced by the feedback from parents/guardians was a need for increased marketing to promote events. One of the parents fed back that they weren't sure that they would attend a CLAPA event again, a point which was related of the lack of attendees. Finally, travelling distance was raised as a potential challenge.

Outcome 3 – Key recommendations (East of England)

- Continue to host events across the region (and encourage volunteers to do to same)
- Increase efforts to market and promote events in order to attract more families e.g., social media, local press.
- Include beneficiaries (e.g., those that show interest in given event) in the decision of the locations which events are to be held in.

Central region

The Central region is defined as: Birmingham, Derbyshire, Herefordshire, Leicestershire, Nottinghamshire, Rutland, Shropshire, Staffordshire, Warwickshire, Worcestershire and parts of Lincolnshire. Claire Evans has been in post as Regional Coordinator since October 2014.

Outcome 1 (Central region)

“Volunteers demonstrate useful and transferrable new skills, feel more confident and better able to deliver support to others affected by cleft.”

Overview

The RC has delivered volunteer training sessions in both group and one-to-one format throughout the year, with both new and existing volunteers.

Feedback from volunteers

The RC obtained feedback from 5 volunteers (1 new volunteer, 4 existing volunteers). They gave the following reasons for attending the training (in order of most frequently reported):

- To learn more about CLAPA
- To find out how to help others
- To give back to cleft services
- To meet other individuals and families
- To refresh knowledge of the Parent Contact role

The volunteers reported the following when asked which aspects of the training event they most enjoyed:

- Networking
- New information
- Scenarios
- New processes
- The RC's
- All training given was necessary

When asked what (if any) aspects could be improved, the volunteers reported:

“More people on the training.”

The majority of volunteers reported having access to a local support network (4/5) and feeling part of a community (4/5) as a result of attending the training. Most fed back that they felt more confident in connecting with others for support (3/5). A minority felt that they knew more people affected by cleft (2/5), which may have been due to the one-to-one training format provided for some and not for others. All volunteers reported being more able to support families and individuals affected by cleft as a result of the training (5/5), and that they had gathered new knowledge and information to help them cope with

cleft-related issues in a positive way (5/5). All parent volunteers reported being more able to support their own child as a result of attending the training (3/3). The majority of volunteers also reported that they gained useful and transferable new skills from attending the training (4/5), and that they felt confident in their role (5/5).

Additional feedback comments included:

“Keep going with the refresher training – it’s good to reconnect and review”

“A one-to-one induction is a quick and efficient way of delivering the training”

In addition, the following comment was provided by a Project Assistant (local cleft team) regarding the benefits of the Patient Voices Group:

“The Patient Voices group has given us great insight into what our families would love to see from the cleft lip and palate service here at the hospital. In order to move forward, it is essential that we develop the service based on the feedback of our families and thus the Patient Voices Group acts as an invaluable opportunity to gather constructive comments. Whilst hearing suggestions of what resources the families would find helpful, it is also great to hear the positive feedback that comes from the meeting; it is a real confidence boost and assures us as a team of the positive impact we are having.”

Outcome 1: Summary (Central Region)

Overall, feedback from volunteers active in the Central region is positive. The continuation of the provision of one-to-one training that was introduced in Year Three appears to be favoured by volunteers, especially for the purpose of ‘refresher’ training. Of the data collected, feedback was mainly from existing volunteers, with substantially less collected from new volunteers.

Outcome 1: Key recommendations (Central Region)

- Continue to train new volunteers in the region.
- Continue to offer one-to-one and group training sessions on a ‘best-fit’ basis.
- Continue to engage with all volunteers regularly and incorporate their feedback into service delivery.
- Maintain contact with the local cleft teams and continue to encourage ongoing collaboration.
- Continue to attend relevant training and networking events in order to build relationships and links with other organisations.
- Additional data collection would be valuable for the evaluation

Outcome 2 (Central region)

“Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental health and wellbeing, enabling them to live fuller lives in which having a cleft is not an issue.”

Overview

The RC has delivered and/or supported a number of events aimed at children and young people, including Residential Weekends, a Christmas party and a 'transition to senior school' day. The RC has also been involved with the Children and Young People's Council, and the Adult Voices Council.

Feedback from children and young people

The RC helped to organise and run a number of Residential Weekends. Fifteen children and young people (CYP), and seven parents (parent-reported child outcomes) provided feedback.

Nine of the fifteen CYPs reported having attended a previous regional event, meaning six were new to CLAPA, indicating that this event is both attracting new children to engage, as well as retaining those that have attended other events organised previously.

The CYP gave the following reasons for attending (in order of most frequently reported):

- To make friends
- To have fun
- To meet other children and young people who have a cleft
- To meet adults who have a cleft
- To offer help and advice to other children and young people who have a cleft
- To learn more about the support I can get from CLAPA
- To give something back to CLAPA

When asked which aspects of the event they most enjoyed, CYPs responded:

- Making new friends
- Having fun
- Reuniting with old friends
- Meeting other people born the same as me

The CYP responded with the following when asked about what aspect(s) of the event could be improved:

"Make it a longer stay!"

The majority of CYPs reported making friends at the Residential Weekend whom they feel they can talk to about having a cleft (12/15). Most fed back that they can now help other CYP affected by cleft (13/15), have learned new ways of coping with cleft-related problems in a positive way (12/15), and feel more confident about themselves (14/15) as a direct result of attending the Residential. Finally, all 15 CYP reported that they would like to attend another residential weekend again in the future.

One CYP commented:

"I have made lots of good friends and I will keep in contact because of CLAPA"

Photographs from the Residential Weekends are provided below, and a feature written for the Birmingham Children's Hospital newsletter is included in the Appendices.



The feedback collected from seven parents of the CYPs who attended a Residential Weekend in Year Four was similarly positive. All seven parents fed back that their son/daughter had enjoyed the weekend, and that the Residential Weekend had been beneficial for their son/daughter.

Furthermore, these parents commented:

"I believe her confidence grows every time she gets these opportunities."

"He meets other children with clefts and doesn't feel like he's the only one."

"They renewed previous friendships from last year's residential weekend. They participated in activities that they wouldn't usually get to do. Moreover, they spent time with people who have clefts and therefore can

directly empathise with. Most importantly perhaps, they had great fun and thoroughly enjoyed the weekend – independent of their family and usual friendship groups.”

“My daughter always returns from these events much more confident, which is amazing as she is often quite under confident at school. She talks about feeling part of something and reassured that her CLAPA friends have had similar experiences to her. Thank you so much for putting these events on!”

“My daughter loves these events. She is always talking about them and can’t wait for the next ones.”

One parent suggested the following to improve residential weekends:

“It would be great for my daughter to have some more teen-focused events, so she can get to know more young people her own age.”

After attending a Christmas party, CYPs provided the following comments:

“It was very fun, exciting, crazy and awesomely cool!”

“It was excellent and fun. Excellent Christmas party!”

“Thank you for our first ever CLAPA Christmas party – the kids loved it!”

Parents also commented the following:

“Another excellent event from the CLAPA team. Thank you for a super afternoon. You all do a marvellous job.”

“Great party with lots to entertain the children. Loved it, thank you all for organising”

One parent responded with the following when asked about anything that could improve the event:

“More activities for older children.”

The following comment was provided by a Health Professional who supported the ‘transition to senior school’ day (see Appendices for more information) held for CYPs and their parents:

“The young people listened intently to a senior pupil with clefts experiences and very much benefitted from hearing how her hearing difficulties did not hold her back. Another senior pupil was very generous in sharing her difficult experiences as a young person and demonstrated what a fantastic person she has become and the achievements she has now made. They were both so positive and are great role models.”

Feedback was collected from 8 CYPs from another CLAPA event. Most of these children were aged 11 and under, and all had attended previous CLAPA events.

The CYPs reported the following reasons for attending (in order of most frequently reported):

- To make friends
- To have fun
- To meet other children and young people with cleft
- To learn more about the support I can get from CLAPA
- To offer help and advice to other children and young people with cleft

When asked what aspects of the CLAPA event they enjoyed most, they responded as follows:

- Meeting other people
- Being part of a group

The CYPs responded with the following when asked about improvements that could be made:

- More events
- More frequently

Further feedback was not collected from all of the CYPs since different evaluation forms were distributed. Most of the CYPs reported making friends at the event that they feel they could talk to about having a cleft. In addition, all the CYPs fed back that they now feel they can offer help to other CYPs with cleft, as a direct result of attending this CLAPA event. Furthermore, the majority of CYPs stated that they have learned new ways of coping with cleft-related problems in a positive way, feel more confident about themselves, and that they would attend another CLAPA event in future.

One CYP who was new to the Children and Young People's Council in Year Four provided a testimonial for this report:

"I went on a residential weekend in August. I was able to speak to the RC at any time and felt comfortable speaking about any worries I had. I haven't been on the council long and had only been to one meeting before the residential weekend so I was quite nervous, but the RC always had something fun for us to do where we all felt comfortable. I haven't been involved in any other activities, but I feel that I would be fully supported by the RC if I was going to."

Feedback from adults born with cleft

Unfortunately, little feedback from adults born with a cleft has been collected during Year Four. However, relevant data was collected from 8 adult volunteers at a recent training day, as well as one volunteer who completed one-to-one training.

As a result of the training, 8/9 adults felt they had access to a local support network, and 8/9 felt they knew more people affected by cleft. All adults indicated that they felt more confident in connecting with others for support with cleft related challenges, and felt part of a community. All adults felt more able to provide support to families and individuals affected by cleft, had gathered new knowledge and information to help them cope with cleft-related challenges, and felt more confident in their role as a volunteer. Most adults (8/9) also felt they had gained new and transferrable new skills. Examples of these skills are given below:

- Providing positive support to others
- How to remain objective given circumstances of support
- Effective listening skills
- Ability to ask people questions
- Time management

One adult provided an additional comment:

“The RC was great, excellently run session, good atmosphere created, feel very supported in my role as a volunteer.”

In addition, the Clinic Volunteer at Birmingham Children’s Hospital, who is also an adult affected by cleft, provided a case study for this report, and was included in a feature in the Birmingham Children’s Hospital newsletter (see Appendices).

Outcome 2: Summary (Central Region)

The activities for children and young people within the Central region this year have been extensive, and have been highly commended by both young people and their parents. The Residential Weekends in particular are widely praised, particularly in relation to boosting the confidence of CYPs, and normalising the effects of having a cleft. In addition, it is extremely positive that CYPs return to attend further Residential Weekends. However, it is equally important to engage more CYPs that have not previously attended and/or not engaged with CLAPA, in order to increase the reach and scope of such positive work. The topic of age emerged regularly in the feedback from events aimed at CYP, from both the young people themselves and their parents. Specifically, there is the feeling that more events need to target older CYPs. Finally, it is important that the RC ensures that the correct version of evaluation forms are distributed to CYPs wherever possible, in order to optimise the evaluation evidence. Feedback collected from adult volunteers was positive. Going forward, additional data from adult volunteers is encouraged.

Outcome 2: Key recommendations (Central region)

- Continue to host events for children and young people of all ages across the region (and encourage volunteers to do to same), building particularly on the success of the Residential Weekends.
- Continue to raise the profile of events such as these in order to attract more participants.
- Consider events and/or activities at existing events aimed at older children and young people
- Continue to support the CYP and Adult Voices Councils, including joint meetings where appropriate.
- Continue to develop links with cleft teams and other organisations.
- Encourage the development of activities and support for adults born with cleft across the region.
- Additional data for the evaluation, particularly from adult beneficiaries would be valuable.

Outcome 3 (Central region)

“Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.”

Overview

During Year Four, the RC was involved in a number of events aimed at families. Events from which feedback was collected include a sponsored walk, a Christmas party, a ‘transition to senior school’ day, and a family fun day.

Feedback from parents/guardians

Thirteen parents/guardians provided feedback at events, four of whom were new to CLAPA events.

Parents/guardians gave the following reasons for attending such events (in order of most frequently reported):

- To meet other individuals and families
- To meet health professionals
- To give back to cleft services
- To learn more about CLAPA
- To find out how to help others affected by cleft

When asked which aspect(s) they most enjoyed, parents/guardians responded as follows:

“Great to feel part of something important to our family.”

Not all parents/guardians completed the same evaluation forms (meaning that the questions asked differed). All those who were asked reported knowing more people affected by cleft (3/3), feeling more confident in connecting with others for support (3/3), feeling more able to support their own child (3/3), and feeling part of a community (3/3) as a direct result of attending the events. All reported having access to a local support network (13/13), and that they would attend another CLAPA event in the future (13/13). A minority of parents/guardians fed back that they felt more able to support other families and individuals affected by cleft (4/13), and that they gathered new knowledge and information to cope with cleft-related challenges in a positive way (4/13). In both cases, all other responses were neutral in nature.

Some parents/guardians reported how they had heard about the event, which may be useful for promotion of future events:

- Facebook
- Clinic volunteer

The following comment was provided by a Health Professional who supported the ‘transition to senior school’ day held for CYP and their parents:

“As always it was really helpful to be able to have representatives from CLAPA join the transition day. For some families, who received a late diagnosis, this was their first contact with CLAPA and they seemed very enthusiastic to hear about the support and activities CLAPA provide (especially the residential). The addition of the comments from the senior pupil was invaluable for parents to be able to hear first hand how she had experienced the transition to secondary school and she had some really useful ideas to share about how parents can support this process. She is a great ambassador for CLAPA.”

Other comments provided by parents/guardians following attendance at regional events included:

“A fantastic day. Thank you so much for organising such a great experience. We had a blast and it was good to meet some new people too.”

Parent Contacts have been active in the region, supporting beneficiaries (over the phone and online) with a range of issues, including emotional support, hearing issues and treatment issues.

Case Studies have also been provided by parents/guardians regarding their involvement with the RC Project (see Appendices).

Outcome 3: Summary (Central Region)

A range of events were held for parents/guardians across the region during Year Four and the feedback that has been collected is positive. The neutral feedback received appears to relate to the nature and the aims of the event. For example, an event such as a sponsored walk or a Christmas party will not provide training for parents/guardians to acquire new skills or information.

Outcome 3: Key recommendations (Central Region)

- Continue to host events across the region (and encourage volunteers to do to same).
- Continue to provide a wide range of activities for children of all age groups at family events.
- Continue to raise the profile of events such as these in order to attract more families
- Collect data on the activities carried out by regional Parent Contacts.
- Continue to have a presence in local cleft clinics.

South East region

The South East region is defined as: Berkshire, Buckinghamshire, East Sussex, Hampshire, Kent, London, Oxfordshire, Surrey and West Sussex. The South East region was the most recent region to be introduced to the project, launching in December 2014. Cherry LeRoy commenced as RC in this region in June 2015.

Outcome 1 (South East region)

“Volunteers demonstrate useful and transferrable new skills, feel more confident and better able to deliver support to others affected by cleft.”

Overview

The RC has delivered a number of training days for both new and existing volunteers, and in both group and one-to-one formats. Volunteer trainees have included a wide range of people, including adults with cleft, partners of adults with cleft, friends of individuals affected by cleft, cleft team members, parents, aunts and uncles, and grandparents.

Feedback from volunteers

Twenty-eight volunteers (eighteen of whom were new to CLAPA) provided feedback following a training session. This feedback is presented below.

Volunteers gave the following reasons for attending (in order of most frequently reported):

- To find out how to help others
- To learn more about CLAPA
- To give back to cleft services
- To meet other individuals and families affected by cleft
- To learn more about cleft
- To meet health professionals
- To learn how to form a local branch

Volunteers responded as follows when asked which aspect(s) of the training they enjoyed most:

- Learning about possible roles
- Meeting other volunteers
- Hearing the stories of others
- The informative and welcoming nature of the training

Volunteers reported the following when asked what they least enjoyed or could be improved:

“Nothing it was all excellent.”

“Perhaps put people in pairs/have group sessions.”

All volunteers who provided feedback reported having access to a local support network as a direct result of attending the volunteer training (28/28). Most of the volunteers fed back knowing more people affected by cleft after attending the training (21/28). However, the seven that did not answer positively to this, responded with a neutral response (no difference), and this is most likely as a result of the training being carried out on a one-to-one basis for these volunteers. All volunteers reported feeling part of a community after the training (28/28), whilst most fed back that they felt more confident in connecting with others for support (26/28), and were more able to support other families and individuals affected by cleft (26/28). Most reported feeling more able to support their own child (16/28), while the remainder of volunteers indicated that this did not apply to them. The majority of volunteers reported that they had gathered new knowledge and information to help them cope with cleft-related issues in a positive way (26/28), and that they gained useful and transferable new skills (22/28) as a result of attending the training. Some volunteers listed examples of new knowledge, information, and/or skills they acquired:

- Up to date knowledge of cleft-related issues and treatment
- How to handle data
- Etiquette when working with children and adults
- Knowing what to say when meeting others – social skills
- CLAPA’s role in UK cleft services

All of the volunteers reported feeling confident in their role(s) (28/28).

Additionally, the following comments were provided by volunteers in different roles:

“The RC travelled to the hospital to spend one-to-one time with me. I appreciated the opportunity to learn more about CLAPA, and to elaborate around the values and functions of CLAPA’s work in the UK. I find the

challenge fascinating and an amazing opportunity for raising awareness for the future. I am excited about joining CLAPA” - Volunteer and Health Professional.

“The RC is a good person to contact who works with the charity, but who you can be honest with in a way that you might not be able to with other office-based CLAPA staff members. The training course was very good and the RC is available if I have questions. The RC is organised and cares and does a great job” - Volunteer and Parent.

“We met to set up a local CLAPA branch. Volunteers were very keen to start the group and the RC has encouraged the group and led the group very well. Starting a branch will be so important to give support, reassurance, non-medical support and face-to-face contact to all families in the local area” – Health Professional.

Outcome 1: Summary (South East Region)

The RC has delivered a substantial number of training days and collected a large volume of positive feedback. As the newest region, feedback collected from those new to CLAPA demonstrates the successful recruitment of new volunteers. Training took place both in one-to-one and group formats over the course of Year Four and the feedback suggests that beneficiaries see positives in both options. Another positive to emerge from the feedback is the wide variety of people being encouraged to volunteer, including adults with cleft, partners of adults with cleft, friends of individuals affected by cleft, cleft team members, parents, aunts and uncles, and grandparents.

Outcome 1: Key recommendations (South East Region)

- Continue to train new volunteers in the region.
- Engage with all volunteers regularly and incorporate their feedback into service delivery.
- Continue to provide one-to-one and group training session formats using a ‘best fit’ approach.
- Continue to develop relationships with the local cleft teams and encourage ongoing collaboration.
- Continue to attend relevant training and networking events in order to build relationships and links with other organisations.

Outcome 2 (South East region)

“Children, young people and adults affected by cleft lip and/or palate report a positive difference to their mental health and wellbeing, enabling them to live fuller lives in which having a cleft is not an issue.”

Overview

The RC helped to facilitate several events in the South East region aimed at children and young people, including a Residential Weekend and various family events. Much less feedback is available from adults born with cleft.

Feedback from children, young people and adults

Feedback was collected from a Residential Weekend (which was facilitated by the RC for the Central Region, on the South East RC's behalf).

Nine children and young people who attended the Residential Weekend completed evaluation forms; the majority of whom were aged 11 years and under (8/9). Most of the CYPs had attended a previous CLAPA event (8/9). The CYPs gave the following reasons for attending the Residential Weekend (in order of most frequently reported):

- To meet other children and young people with cleft
- To offer help and advice to other children and young people with cleft
- To make friends
- To have fun
- To learn more about the support I can get
- To meet adults with cleft
- To see my CLAPA friends in person rather than on the phone

When asked which aspect(s) they enjoyed the most, the CYPs responded as follows:

- Activities
- Being in a group of friends
- Being away from home/being independent

The CYPs gave the following responses when queried on which aspect(s) they least enjoyed/which area(s) could be improved:

- Stay for longer!
- The food
- The rooms/beds

Furthermore, all of the CYPs reported that they made friends who they can talk to about having a cleft (9/9), as well as feeling that they can offer help to other CYPs with cleft (9/9). The majority of CYPs reported feeling more confident about themselves from attending the weekend (8/9), as well as learning new ways of coping with cleft-related problems in a positive way (6/9). All of the CYPs stated that they would attend another event like this in the future (9/9).

Some of the CYP provided comments on the Residential Weekend:

"I had fun spending time with other people with clefts and getting to know them. I feel like I'm more confident talking about it now."

"I loved having more conversations with friends I don't see very often."

"I had an amazing time and have loved meeting new people and having fun with friends."

One of the Residential Weekend attendees also provided a Case Study for this report, which is included in the Appendices.

Parent feedback on the Residential Weekend was also acquired by the RC, with all parents/guardians reporting that their child/ren had enjoyed the Residential (27/27). One parent/guardian provided the following comment:

“Can you please add our daughter to the list to attend the next Residential Weekend. She has mentioned that she made two friends on previous Residential Weekends and is hoping she will meet up with them again.”

In addition, parents/guardians provided comments on the impact of events aimed at families (such as the Family Fun Days) on their child/ren:

“Throughout the early stages my daughter was blissfully unaware and just like any other kid. But as she got older and encountered other older and unknown children more the questions started to come and that's when we realised just how important it is for her to have the opportunity to meet and hang out with other children who might look a bit different...and have the chance to explore whatever questions might be going on in her head. We know from comments and conversations that happened after the event, and from conversations with my daughter's teacher, about the positive impact it has had. Going forward, it will also be important for her younger sister to attend events and see that other people have different faces too.”

“These events have made such a difference to my daughter, being able to talk to others who have experienced operations and situations similar to her has helped boost her confidence. She is due her next operation soon so this has happened at a perfect time for her. She has mentioned two other girls she has made friends with and is hoping to meet up with them again.”

“Lovely for my son to have access to other children who share his experiences and challenges.”

“It has been fantastic for my daughter to see other people like her.”

“This event has spread awareness via sponsorship and sharing the event on Facebook.”

“My daughter has met other cleft children and had a wonderful day out.”

“My child got involved in helping to prepare the event, which was great to see.”

“My daughter likes going to these events as it makes cleft a more positive thing for her.”

One Case Study was provided by an adult about their experiences as a regional volunteer (see Appendices). In addition, a small amount of feedback has been collected from adults with cleft who volunteer with CLAPA. All adult volunteers reported having access to a local support network (9/9), as well as having learned new ways of coping with cleft-related issues (9/9). Furthermore, Peer Contacts are active in the South East region, helping with enquiries from other adults and young people with CL/P such as treatment options and coping with bullying and teasing.

Outcome 2: Summary (South East Region)

The activities that the RC has organised and/or supported for CYPs have been appreciated by the young people themselves as well as by their parents/guardians. The Residential Weekends in particular are highly

commended. It is evident from the feedback that CYPs return to take part in these events again. It would also be positive to attract new attendees to the Residential Weekends in the future. In addition, the majority of Residential Weekend attendees are aged 11 years and under. It would also be beneficial to try and cater for, and attract more CYPs aged 12 years and above. Both CYPs and parents provided many positive comments on the Residential Weekend and other family events. It is apparent from such comments that the regional events provide opportunities for CYPs to meet others, socialise and make friends, as well as impacting on their levels of confidence. A minority reported still lacking in confidence, as well as not feeling like they learnt new ways of coping with cleft problems, which suggests that some attendees may need more support than others.

A reasonable amount of data was collected from adults during Year Four, all of which was very positive. Going forward there is need for a solution to engage adults with cleft in providing feedback to improve future service delivery.

Outcome 2: Key recommendations (South East region)

- Continue to host events for children and young people of all ages across the region (and encourage volunteers to do to same)
- Endeavour to host more Residential Weekends in the region.
- Encourage the development of more activities for adults born with cleft across the region.

Outcome 3 (South East region)

“Parents or guardians of child(ren) with a cleft feel less isolated and feel able to support their child in a more positive way.”

Overview

The RC facilitated a number of events aimed at families, collecting a substantial amount of feedback from parents/guardians. Events from which feedback was collected include family fun days, sponsored walks, Happy Faces group meetings, and Branch meetings.

Feedback from parents/guardians

Twenty-seven parents/guardians provided feedback after attending a regional event, 20 of whom were new to CLAPA. Parents/guardians gave the following reasons for attending events (in order of most frequently reported):

- To meet other families and individuals affected by cleft
- To give back to cleft services
- To find out how to help others
- To learn more about CLAPA
- To meet health professionals

- To raise money for CLAPA
- To support the cleft team
- To support family members/people they know affected by cleft

When asked which aspect(s) they enjoyed most, parents/guardians responded with the following:

- Friendly atmosphere
- Speaking with other parents and meeting the children
- Raising awareness
- Seeing the children enjoy themselves
- Sense of community
- Children having the chance to interact with other children with cleft
- Learning how we can give back by volunteering for CLAPA

Parents/guardians reported as follows regarding aspect(s) that they least enjoyed or could be improved:

- Advertise more to gain more support
- More of these local events
- Find ways of supporting parents to contact each other – set up a network
- More funding

The majority of parents reported positive impacts as a direct result of attending regional events. Most reported having gained access to a local support network (26/27), and knowing more people affected by cleft (26/27), while all reported feeling part of a community (27/27). All parents/guardians reported feeling more confident in connecting with others for support (27/27). The majority reported being more able to support other families and individuals affected by cleft (24/27), feeling more able to support their own child (25/27), and having gathered knowledge and information to help cope with cleft-related issues in a positive way (22/27). Finally, all parents/guardians stated that they would like to attend another event in the future (27/27).

Some parents/guardians provided the following additional comments on the event they attended:

“Fantastic opportunity to meet others, share stories and support one another. Great event, thank you!”

“We feel like we are part of the CLAPA community, it’s been very positive for us as our first family event.”

One parent commented on how the RC acts as a gateway to finding peers with similar experiences:

“The RC introduced me to another cleft parent who had recently been through the same ‘sending your child to school for the first time’ experience, which was very beneficial.”

Another positive that emerged from the event feedback was the variety of people attending, which included children with cleft, siblings, uncles, aunts, grandparents, and some expecting parents.

In addition, the RC acquired a Case Study from one parent/guardian, which can be found in the Appendices of this report.

Outcome 3: Summary (South East Region)

A number of events were held across the South East region during Year Four, which were specifically aimed at parents/guardians and families, and the amount and content of feedback was positive. It was clear that some events were attended by parents expecting a baby with CL/P, which is a notable development and something which could be further explored. Equally, the variety of people attending events is a highlight of Year Four, and could be built upon going forward.

Outcome 3: Key recommendations (South East Region)

- Continue to host events across the region (and encourage volunteers to do to same).
- Look at ways in which events can cater for a variety of attendees, including uncles, aunts, grandparents, and expectant parents.

Additional activities (East, Central and South East regions)

All RCs have been involved in additional National activities during Year Four, demonstrating their efforts to work collaboratively across regions. The RCs offer support to one another, meeting regularly to discuss the project as a whole, and to share achievements and challenges. The RCs will occasionally facilitate/help to facilitate an event in a region which is not their own in order to learn from one another, and to ensure the events go ahead and are delivered to a high standard.

In addition, the RCs contributed towards Cleft Awareness Week in May 2016, and played a key role in securing matched funding to support the continuation and expansion of the RC Project as a whole. They are also involved in the running of the regional Facebook groups, and produce regional newsletters on a regular basis.

Finally, the RC Project as a whole is guided by the Regional Coordinators Project Advisory Group (RCPAG), which meets once per year and provides ad-hoc support throughout the duration of the project. The RCPAG consists of CLAPA staff, CAR staff, patient representatives (including two parents, a member of the CYP Council and a member of the Adult Voices Council), members of the local cleft teams and representatives from two related charities (ChildLine and the National Deaf Children's Society). The group met twice during Year Four to discuss the progress of the project and its evaluation.

Final summary (East, Central and South East regions)

This evaluation report has outlined the progress made in all three regions toward the three main outcomes of the RC project.

The RC project has grown steadily across the four years, delivering a service that individuals and families affected by cleft value. In addition, the project is highly commended by Health Professionals. Recommendations are outlined in this report based on the evidence collected, and according to each

region. RCs are encouraged to consider the specific recommendations for their region along with the overall aims of the project.

The amount of evaluation data collected is stronger in some areas than others, with feedback from adults born with cleft being the most limited. Going forward, this is an area that requires further development, particularly in terms of the amount of events/avenues of support aimed at adults, which would subsequently lead to more feedback data from this group.

Overall, feedback across events and regions is largely positive. The minority of less positive feedback, rather than being negative is neutral (i.e., 'no difference'). As mentioned, this is most likely in relation to the nature and purpose of the events from which feedback has been collected. Tweaks to the programme of events to include some skill, information or knowledge acquisition could be beneficial.

The Residential Weekends continue to be a great success and a strongly positive aspect of this project. Residentials are highly commended by CYPs and parents alike. Going forward, it may be beneficial for the RCs to build further on facilitating a positive impact on CYP's confidence and social skills. In addition, targeting and attracting more children aged 11 years and above, as well as continuing to try to attract CYPs who are not currently engaged with CLAPA would be beneficial.

It is recommended for the RCs to continue to offer volunteer training in both group and one-to-one formats on a 'best-fit' basis, since feedback indicates that there are potential pros and cons to each.

Finally, RCs should continue to utilise creative and novel advertising and marketing approaches to promote events, in the hope of attracting more attendees.

Appendices

Appendix 1: Case study from a Clinic Volunteer (Central region)

For the last 16 months, I have been volunteering in Birmingham Children's Hospital as a CLAPA Volunteer in the weekly Cleft Clinic. My role is to talk to parents about the support CLAPA can offer, as well as upcoming events and activities. This has been both challenging and rewarding, and I am proud to say that I believe that I have had a positive effect on many of the people I have met.

Going into clinic for the first time was very nerve-wracking. I am not a confident person, and I have never been comfortable talking about my own cleft with others. Fortunately, the staff at the hospital were very friendly and supportive, and after a few initial hurdles, I began to feel more confident.

In clinic, I approach families and ask them whether or not they have heard about CLAPA. Many have, and are happy with the support they have already received, or have reached a stage where they feel that the services of CLAPA are no longer of use to them. Some even ask me how they can raise money for CLAPA as a thank you, and to raise awareness.

I also inform parents about upcoming events, and the work of the West Midlands Branch. I hand out leaflets advertising our events, and often I find this is a great way to get people interested. Since becoming a volunteer, I have also become Vice-Chair of the West Midlands Branch, and through my work at clinic, I am pleased to say that attendance at our events has increased dramatically. I have even had parents ask me how they can become volunteers and join the committee.

One of the events that I have really enjoyed promoting is the Residential Weekend for children aged 9-16. Many of the parents I spoke with at clinic thought that the weekend was a great idea, and the children who came absolutely loved it. I also attended the weekend, and I was really pleased to see how many of the children grew in confidence over the weekend.

The clinic is often crowded and noisy, and it can be difficult to approach people to talk about something that they themselves may not wish to discuss. There is often a language barrier, which the West Midlands Branch has tried to remove using leaflets printed in different languages. Most parents are happy to talk about their child, and I have found that some parents find it very reassuring to talk to an adult who has a cleft – many comment on how it helps them to see how their child may look after their surgeries have finished. When I started volunteering, I never thought that parents would have thought that, and my experience in clinic has really helped to build my own confidence and become more open about my own experience of having a cleft. I have also found it really rewarding to build relationships with the children, and to see them coming to our local events and meeting other children with clefts.

Some weeks in the clinic are very difficult, but overall I have found the experience to be very beneficial. Sometimes I will have a week where no one is interested in talking to me, but then I meet a mom, dad, grandparent or child who really wants to know about CLAPA and share their experience with me. Then it is all worthwhile.

Appendix 2: The Birmingham Children's Hospital CL/P newsletter (Central region)

FOURTH EDITION
MAY - JUNE 2016

COLOUR & CLEFT

The BCH Cleft Lip and Palate Team are running the Birmingham Colour Run in August 2016. Keep an eye out in clinic if you would like to sponsor the team!



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Birmingham Children's Hospital 
NHS Foundation Trust



CLEFT LIP AND PALATE
NEWSLETTER

You're invited.

Transition Day 2016

Is your child starting secondary school in September? Held right here at BCH, we will be hosting a 'Transition Day' (Thursday 14 July 2016) so that your child can be supported in their transition between primary and secondary education.

The day consists of everyone meeting together and taking part in some group activities to get to know each other. This will be followed by two groups running in parallel, one for young people and one for parents/guardians. The young people's group aims to help them develop practical skills, for example:

- Increase confidence in meeting new people.
- Coping with the changes in routine and the new demands of attending secondary school.
- Dealing with curious questions and teasing/bullying if it occurs.

If you and your child would like to attend, please email Cleft.Services@bch.nhs.uk or call **0121 333 8235** by Monday 13 June 2016.

Thank You

Jamie's Marvellous Marathon!



Jamie is jumping for joy with his unbelievable effort of fundraising £4,571.22 for the team. Jamie Griffith's son Arthur was born with a bilateral cleft lip and palate and due to his positive experience with both the team and the BCH Parent Accommodation, Jamie kindly offered to fundraise for us by running the 2016 London Marathon.

Having impressively met his initial target of £2,500, Jamie went on to smash his original goal by miles. We here at BCH are extremely grateful for such efforts (particularly with an event as physically and mentally challenging as a marathon!). We as a team hope to keep up the good work and commend Jamie for such a fantastic achievement. A massive thank you from everyone here in the BCH Cleft Team!

CLAPA Residential Weekend



CLAPA are organising a Residential Weekend in Staffordshire for children and young people with a cleft lip and/or palate aged 9-16 years.

VENUE: Kingswood Centre, Staffordshire, WV7 3AW
DATE: Friday 22nd - Sunday 24th July 2016



Residential Weekends are all about having fun and are based around outdoor activities including tag rugby, environmental games and indoor craft activities. The Residential Weekend is also about giving young people born with a cleft, the chance to meet with others who have the same condition in a safe and fun environment. Many children who attend have never been on any CLAPA activity before but soon feel at home, especially after spending the night chatting in their dorm rooms!

To apply for a place or for more information, please get in touch with Claire Evans at claire.evans@clapa.com or call 07792 772362. Register online by clicking [here](#).

CLAPA Awareness Week

A booming success, Awareness Week concluded on Sunday 15 May 2016 with our very own dental trainee Mary Connolly walking the 'Sponsored Walk' held in Arrow Valley Park, Redditch; raising £140 for the cause. Whilst we are still waiting to hear the total amount raised over the week, the event meanwhile confirmed the strength of the cleft community and ever-growing support available for our families. Thanks to Mary, CLAPA and all involved in organising and participating in the event.



Mary (left) and Kathy

An additional thank you to CLAPA volunteer Kathy Parker who has helped support the team in our Wednesday clinics whilst introducing the resources that CLAPA has to offer. We as a team look forward to continuing our partnership with Kathy and the CLAPA team in order to provide the best support possible for our patients.

Appendix 3: Case Study from a parent/guardian (Central region)

On 24th Feb 2016 I attended the 1st CLAPA Patient Voices meeting which was held in Birmingham. It was a great opportunity to meet new people who understand the range of emotions, challenges and appointments which affect patients and families of those with clefts.

As a mother whose daughter was born with a bilateral cleft lip and palate, I was able to speak to other parents, teenagers, young adults and medical staff in an informal gathering, where we were able to openly share problems, anxieties which we had all encountered, and suggestions for passing on information to patients or the way appointment days are structured.

Looking forward to the next meeting with a few more members and hopefully improve an already great service provided by CLAPA and Birmingham Children's Hospital. Here's to raising cleft awareness Nationwide!

Appendix 4: Case Study from a young person who attended a Residential Weekend (South East region)

I decided to go on the CLAPA Residential Weekend in Cudham because I was having a bit of a hard time at school, feeling like everyone was looking at me and wondering if my friends really liked me. My confidence was very low. I had been on previous CLAPA weekends and had found that sharing experiences and having a laugh with other kids with clefts had really boosted me. I talked to my mum and dad about going on the weekend and they were encouraging.

Because I had been on a weekend before I wasn't as nervous. The first time I had no idea what to expect, I had never met anyone else with a cleft before. All the girls in my dorm were so kind and amazing that I quickly felt really comfortable. I was looking forward to seeing some of them again at Cudham. It was also nice to see the adults again too as I got a lot of positive feedback from them at the first trip and help from everyone with a presentation at school that I was doing about having a cleft.

Cudham was a beautiful place in the forest and the lady who ran the centre was really welcoming and made delicious food. There were so many brilliant activities, exploring the woods, tag rugby, den building and making campfires and a disco. We also spent lots of time chatting in our dorms. It was really nice that some of the adult helpers were just a bit older than me in their 20's. They seemed really confident and I felt inspired by them.

Every time I leave to go home after a CLAPA trip I burst into tears because I've had such an amazing time. When I go back to school I know I feel a little bit proud to have a cleft I feel much more confident. I wish there were more opportunities to meet other teens with clefts.

I would recommend this trip to all kids with clefts. I have so many amazing memories and I can't wait to go on another CLAPA camp.

Appendix 5: Case Study from an adult born with cleft lip/palate (South East region)

I am an adult with a cleft lip and palate and became a volunteer for CLAPA in 2012 and decided to join the Adult Voices Council (AVC) as due to my age (over 50!), I felt a role in supporting adults was best. I then became Co. Chair when the existing chair Jonathan Clarke had completed his term. Tony Ruel and I met on the Induction Day, are of similar ages and a shared role has worked well. The role involves helping to run AVC acting as a voice for adults affected by a cleft across the UK and forming ideas for CLAPA Adult Voices, promoting awareness of services from CLAPA and the NHS Cleft Teams and informing and maintaining contact with CLAPA National. The Chair's role is to share tasks with other AVC members, set agendas, encourage new members and maintain regular contact with CLAPA National on the progress we make.

CLAPA is important to me as having a cleft means having had experiences both clinical and usually psychologically as part of my life. It is good to know CLAPA is there to help children, their parents and adults affected by clefts. Being a volunteer is important to me because I feel I can help others and having a cleft puts me in a stronger position to do so. This is why I trained as a Peer Contact in 2014 so that I could formally provide that support. They typically need someone to talk to who fully understands some of the issues you can face in your journey through life including the need for further clinical treatment. We are not counsellors more a listening ear who can signpost people to get the right help. Helping people and making a difference is clearly what I get out of being a volunteer.

NHS Cleft Teams – Developing relationships with the help of Regional Coordinators is important so that Cleft Teams are aware of the progress AVC are making and to encourage them to refer adult attending their clinics to be aware of CLAPA AVC and refer the services they provide in supporting adults with clefts.

Dental Schools – There are 19 Dental Schools in the UK and AVC are beginning to make presentations to students to make them aware of Clefts, supplementing the minimal training they receive. The first one was conducted by AVC member Emma Heesom in May at the Cardiff Dental School where students were given a great presentation and included Emma's own cleft story."

Appendix 6: Case Study from a parent/guardian (South East region)

When I went for what I thought would be a routine 20-week scan, I was told rather brutally that my baby had a "harelip" and my whole world fell apart. The walk from radiography back to ante-natal, clutching my two-year old in one hand and my £5 scan photo in the other, was the longest of my life. I'd been through medical problems with my first child but it was fear of the unknown and the prospect of a lifetime's problems for my baby which frightened me the most.

Somewhere in the turmoil I found the phone number for CLAPA and, although it was only a day or so before Christmas, I found a friendly and reassuring voice at the end of the phone which made me feel I wasn't alone.

In the weeks that followed, I underwent an unpleasant amniocentesis to see if any other problems existed and I also had a state-of-the-art (for 1995) scan where they watched my baby swallow to see if the palate was intact (it was almost non-existent). Hard to believe, in this day of 3-D colour scans, that things were relatively basic then. In fact, I was told that it was uncommon for a cleft to be picked up at a 20-week scan.

My whole NHS experience 20+ years ago wasn't the best. In addition to the radiographer's poor bedside manner, I also had to fight opposition from my obstetric consultant because I wanted to "go out of my Health Trust" to use a plastic surgeon I had read great things about. The early diagnosis had given me time to do some research. Although my consultant pretended not to know who the surgeon was, the student medic sitting in told me afterwards that he knew of the surgeon and his great reputation. I stood my ground and, despite long journeys every week with a newborn and a toddler to see the surgeon, orthodontist and cleft team, my choice was vindicated by spectacular results for my son.

From the first contact, CLAPA have supported me giving me advice and reassurance through my ante-natal tests, the birth, the many appointments and subsequent surgeries my baby had to undergo and the difficult learning curve of feeding a cleft baby. I don't think I could have got through it without them and I know my son, now an adult, still enjoys interacting with the CLAPA community via social media.

My family were also incredibly supportive providing both emotional and practical help. I was grateful to the hospital cleft team for loaning me a "before and after surgery" book to show to my friends and relatives. This was pre the internet and it was helpful to show everyone outcomes on

babies with clefts like my son's. I guess this information and support is now easily available on social media and I'm always amazed to see the incredible results.

We took loads of photographs of our son both before, during and after surgery. As a 7-year old he was very proud to take some in to "Show and Tell" at school and he remains fiercely proud of his cleft journey. I need not have worried on his behalf. At school he was always confident and enjoyed (and still enjoys) drama and public speaking.