



Cleft Lip and Palate Association
Cleft Community Regional Support

Project ID: 001028788

End of Year 2
(April 2018 – March 2019)

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1. Introduction to the report

CLAPA is a national charity which supports people affected by cleft lip and palate. CLAPA's vision is:

"A society where having a cleft lip and palate is no barrier to achieving your desires and ambitions."

In March 2017 CLAPA was awarded a 3 year grant from the Big Lottery Fund for its Regional Coordinators Project. The funding enables CLAPA to employ three Regional Coordinators who develop and deliver activities in three regions across England aimed at supporting individuals affected by cleft.

Purpose of the report

The Regional Coordinators (RC) Project has now completed its second year of operation. This report reviews the activities and outcomes delivered by the project in the second year - the period April 2018 to March 2019.

The report provides:

- a summary of the project model: how the project delivers activities and outcomes
- a review of the activities and outcomes delivered in the second year and comment on the extent which the project has achieved its targets in year 2
- identifies the issues and challenges which have impacted on the capacity of the project to deliver its anticipated outcomes to date and the learning from the project.

Introduction to the Regional Co-ordinators project

The Regional Coordinators (RC) Project employs RCs in each of three regions of England (East, Central and South East).

The role of the RC is to develop and deliver activity which creates opportunities to bring together people affected by cleft (children and young people, adults and parents of children with cleft). These opportunities serve to reduce isolation, enable people to build supportive peer networks and to build confidence and capacity to deal with the challenges associated with cleft.

RCs directly deliver services and activities, but much of the activity aimed at parents and families is delivered through a network of volunteers. Consequently, a key element of the of the role of the RC involves recruiting, training and supporting volunteers.

Volunteers are at the heart of the project, and are involved in the design, development and delivery of events and services for people with cleft. Volunteers organise family events which bring families together to support each other, they organise fundraising events and events to raise awareness of cleft. Volunteers deliver Happy Faces Groups which provide support for new parents of babies with cleft. Volunteers also provide an accredited peer support service to other parents and to adults with cleft.

Many of the volunteers are people who are themselves affected by cleft, for example parents of children with cleft who want to 'give back' by supporting other parents, and adults with cleft who want to support younger people with cleft.

The diagram on page 3 describes the project model and the key role of volunteers in the delivery of services for parents and for adults with cleft.



3 Regional Co-ordinators



Supported 116 Volunteers



Volunteers deliver



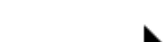
Numbers of people supported



Peer support to 49 parents



Peer support to 28 adults



Supported 65 Families



482 parents, 252 children with cleft, and 388 siblings and other family

Regional co-ordinators also deliver Family Events

Volunteers also take part in



Fundraising



Clinic volunteers



Patient Voices Groups



Raising awareness



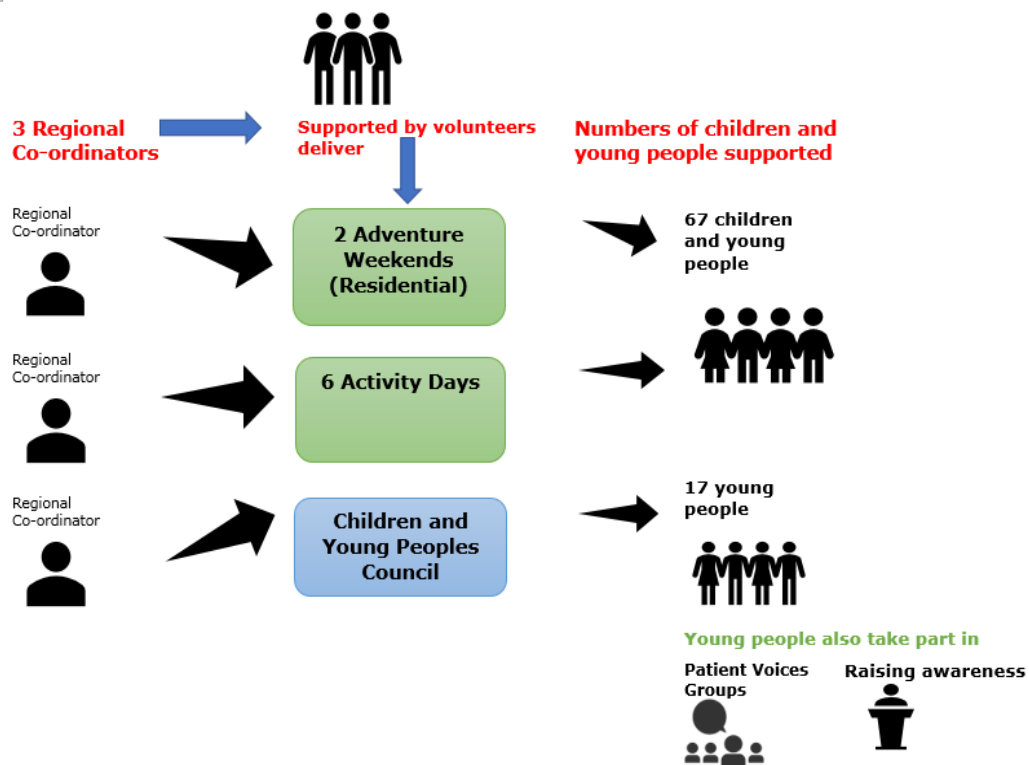
Children and young people's events



The report provides further detail of the activities, the number of people affected by cleft who are engaged through each of the services and the impact of their involvement in CLAPA.

RCs also deliver events to engage children and young people. Many children and young people have never met another child with cleft (around one in 700 children are born with cleft), and often feel like isolated in dealing with their challenges. The events and activities aim to bring children and young people together to meet others with cleft, reduce their feeling of isolation, and develop peer-support networks which build their confidence help young people develop a more positive self-identify.

The diagram below summarises the activities and the number of children and young people who have engaged in 2018/2019.



2. Volunteers

Recruiting and supporting volunteers

In the last year, the three RCs have:

- supported 89 existing volunteers to deliver services:
 - 33 in Central
 - 13 in East of England and
 - 43 in South East
- recruited and inducted 23 new volunteers

In total the RC project has supported 116 volunteers in 2018/19.

The RCs delivered two Volunteer Development Days in the last year and delivered one-to-one training to volunteers who cannot attend group training.



***87% feel more confident in their role as a volunteer as a result of attending the Development Days**

*The 13% who did not feel more confident as a result of development days were long standing volunteers who had attended many training sessions over the years.

Volunteers at a training day in London in March 2019

Effectiveness of Training

- 81% said that the Development Days were 'very effective' or 'extremely effective' in supporting them in their role as a volunteers.
- 19% said the Development Days were 'moderately' effective'

Did people learn new skills?

- 87% said they learned new information and gained skills which would help in their volunteering role.
- 13% said there was no change in their skills/knowledge

What do volunteers do?

As reported in the Year 1 report, CLAPA carried out a review of its structure in 2017/18 which resulted in the dissolution of the local Branch structure. Volunteers now organise around functional groups which have a greater focus on delivering activities or events.

Volunteers deliver events and services to parents and families affected by cleft. This section summarises the types of activities delivered by volunteers across the three regions.

Events Groups: groups of volunteers who organise and deliver local events for parents and families to meet other families affected by cleft in an informal setting and develop supportive peer relationships. Some events groups organise fundraising events and awareness raising events providing further opportunities for families and children to get together in informal settings.

Happy Faces Groups: These are volunteer led groups which provide peer-support for new parents of children born with cleft.

Parent Support Service: The service is managed by the RCs and delivered by trained volunteers. RCs receive the requests for support and match the applicant with a volunteer who has experience of similar issues who provides peer support. Volunteers provide support via telephone or email. CLAPA has recently achieved the APS standard for its Peer and Parent support Services.

Clinic volunteers: Volunteers who provide support and information to parents /families who are attending clinics. They provide a friendly welcome to families at clinics, can provide (non-medical) support and advice to families and signpost them to other forms of support: CLAPA Facebook Groups, Family events in their area, Happy Faces Groups, children and young people's events etc.

Patient Voices Groups

RCs support volunteers to engage with statutory services (NHS) through Patient Voices Groups. These are designed to meet the NHS service specification requirement for the patient voice to meaningfully influence NHS practice and the patient experience in the area of cleft treatment.

- CLAPA facilitates 2 Patient Voices Group, one in East of England and one in Central. A mixture of adults, parents and young people with a cleft are members of the Central group.
- There are 10 members in the Central group and 6 in the East of England group (a mixture of adults, parents and young people with a cleft)

Case study: Patient Voices Groups

Motivation for getting involved in the Patient Voices Group

My daughter was born in 2010 with a bilateral cleft lip and palate and is treated by the team at Birmingham Children's Hospital (BCH).

I already volunteer with CLAPA as Parent Supporter, but was also keen to join the Patient Voices Group as I thought being involved with this group would directly benefit families who receive treatment from BCH.

What has the Patient Voices Group achieved?

Being in the Patient Voices Group has given myself and the other members the opportunity to raise with the Cleft Team several points that we encountered during our experience of the treatment process which felt could be improved or changed e.g. the pre-op information that we were given.

What have you got out of being involved in the Patient Voices Group?
The group is a great way to meet with others who are going through or have been through the treatment process, to meet staff from various areas of the cleft team and to help improve the future of families affected by clefts at BCH.

Awareness raising talks

Volunteers are involved in delivering awareness raising talks. These can be aimed at raising awareness of cleft among the public or raising awareness of parents/families experiences of cleft with medical staff.

CLAPA was invited by teaching staff at Birmingham City University to deliver a training input around the impact of cleft for trainee midwives.

In March 2018, a volunteer spoke to the students about her experiences as a parent of a child with cleft.

The session was really productive: all of the trainee midwives identified new learning and each could identify how they would change their practice in future as a result of what they had learned

What have you learned?

- *Knowing where to refer parents who have a child with cleft palate and the support systems in place*
- *Did not realise the impact cleft can have on a person for years into their lives*
- *Impact on families from 20 weeks to their children attending school and growing up*
- *More aware of what parents may be going through. What services that you can refer families to*

What will you do differently as a result of what you've learned?

- *Sign post to CLAPA services. Probably feel more confident talking to a cleft family*
- *Knowing how to refer to CLAPA and what services are available from them*
- *Awareness to signpost to CLAPA. Understand level of support required particularly with feeding*
- *Ensure families with a diagnosis of cleft are given contact information to enable their access to CLAPA and support groups with families going through a similar journey*
- *Talk to families about their diagnosis, open communication*
- *Feel able to refer parents to support like CLAPA*
- *Be aware of the anxiety among parents and know where to advise them for help and support. Encourage expressing milk to feed baby*

For the volunteer it was a positive experience

"I thought yesterday was great and felt proud that I could pass my experiences on to help midwives understand how CLP affects the whole family for life. Really pleased with the feedback and can't wait to do it again"

The School of Nursing and Midwifery recognised the value of the session and invited CLAPA to deliver to a larger cohort of student in 2019.

Two sessions have already been delivered by volunteers in 2019, with a total of 40 trainee midwives benefitting from the volunteer's experience.

Volunteering at children and young people's events

Some volunteers support RCs to deliver activity days and residential events for children and young people with cleft. Often these volunteers are young adults with cleft who not only support the practical delivery of the events, but also act as role models to the children and young people.

One of these volunteers is O. He is 20 years old, and like many of CLAPAs volunteers, he volunteers in a number of different roles:

- He volunteers at weekend residential events for children and young people with cleft.
- He has volunteered at a transitions day workshop delivered by Birmingham Children's Hospital.
- He is a member of the Patient Voices Group.
- He was a member of the volunteer group that delivered a family event at Christmas 2018.

In the case study below, 'O' explains his motivation for volunteering, what he gets out of volunteering and the impact that volunteering has had on him.

'O' has recently been nominated by his employer for a 'Volunteer of the Year' award to recognise his volunteering. This is O's story.

My motivation for volunteering

I was born with Cleft and Palate myself and CLAPA supported my mother when I was born so I really wanted to give back. I also felt like I could use my experience to help younger people who are growing up with a cleft and act as a role model and an example of someone who hasn't let a cleft hold me back in achieving what I would like to do.

When I started volunteering with CLAPA I quickly realised how influential they are in helping build the self-esteem and confidence of young people with cleft. I knew straight away I wanted to be more involved with CLAPA's work and help make a difference.

The residential trips are definitely my favourite part of volunteering. We take the children zip wiring, abseiling, quad biking, camping and much more. It's lovely to see the big smiles on all their faces. However what I most love about the trips is that the children can openly speak about their cleft without the fear of being judged. This really helps them realise they are not alone and they've got loads of people to support them through their cleft journey.

One of the most lovely memories I have with CLAPA was seeing a 12 year old re-assuring a younger child not to be worried about their upcoming bone graft operation by sharing his own experience.

Impact of volunteering

I never thought that by volunteering with CLAPA it would make a difference in my own life.

Before I joined CLAPA I've never met anyone my age with a cleft and now I've made many new friends. I had an upcoming operation on my nose and I was able to ask a few questions to the other volunteers who had it done.

There is also no words to explain the good feeling you get inside when you read the good feedback left by the children after a residential trips. They all say that they feel more confident within themselves and have made new friends. I feel so proud to be part of a charity that enables this to happen.

Impact of volunteering

80% of volunteers said that they had gained skills and experience through volunteering which were useful in other areas of their life.

“Working with others, diversity, understanding, compassion, objectivity”

“Communication skills, being able to support others, networking skills”

Many of CLAPAs volunteers are people affected by cleft: adults with cleft and parents of children with cleft so CLAPA is also interested in finding out if volunteering has an impact on their capacity to deal with cleft related issues in their own lives.

Table 1 shows the results from a survey of volunteers in 2018/2019. It demonstrates that volunteering for CLAPA also contributes to helping people to address the challenges associated with cleft:

- 80% of volunteers felt more confident
- 93% more connected to a community of people affected by cleft
- 80% had learned some coping mechanisms that helped them to deal with cleft-related issues in their own lives in a positive way

Table 1: Volunteer survey

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/R
I am more confident	40%	40%	20%	0	0	
I feel more connected to a community of people affected by cleft	40%	53%	7%	0	0	
I have learned some coping mechanisms that help me to deal with cleft-related issues in my own life in a positive way	27%	53%	13%	0	0	7%

Conclusion and learning

Volunteers are the lynchpin in the services delivered by CLAPA. The diagram on page 3 demonstrates the impact of volunteering on the provision of services for families affected by cleft. Over 400 families affected by have been supported through the efforts of our volunteers.

The role of the RC is critical in recruiting and supporting volunteers to deliver these services. In 2018/2019 the RCs recruited and provided induction training for 27 new volunteers in the year, and supported 89 existing volunteers.

The issues and challenges in recruiting and supporting volunteers are:

Reduction in number of volunteers/loss of trained volunteers

Like many other volunteer-engaging organisations, we have experienced a loss of trained volunteers in the last year. The reduction in the number of volunteers has impacted on the number of events that have been delivered in the last year:

- The South London and Surrey Group usually organise a summer event for parents/families in their area, but did not deliver an event this year due to loss of volunteers. The RC is working with the group to recruit new volunteers.

To address the issue of loss of volunteers we piloted targeted recruitment for parent supporters with specific experience which was successful and will mean we can try this method for other roles.

Low turn-out for volunteer for training/development

Volunteers report that they find it challenging to find time to attend training and development sessions. While CLAPA continues to deliver sessions to meet need, the low turnout/delivery of additional sessions is not cost effective.

To address the issues we have adapted our volunteer development days as a result of feedback from volunteers:

- we have introduced 1:1 and on-line training as a result of feedback
- we have delivered joint training with Rhett UK to share the cost of training

Volunteers also get regular supervision from RCs – 82 supervision sessions have been delivered in the period 2018/2019.

Volunteer involvement in the design and delivery of services.

Volunteers drive the development and delivery of services. Group volunteers decide which type of events that they would like to deliver and the RC's work with them to ensure they meet our guidance.

However, as the number of volunteers in each region is different, and the skills and interest of local volunteers varies, the 'infrastructure' varies in each region.

Consequently, the number of events and types of events delivered in each region varies:

- In South East there are 4 events groups, that deliver local events and fundraising activities, but no Happy Faces Group.
- In Central, there is 1 events group and 4 Happy Faces groups

To address the issue of the lower number of events groups currently operating in Central Region, the Regional Co-ordinator has directly delivered some family events to provide opportunities for families in that area.

3. Impact of the RC Project

This chapter reviews the outputs and the outcomes (against targets) which have been delivered by the RC Project in year 2 of the project.

In May 2018, CLAPA reviewed its outcomes and indicators with BLF. The new outcomes and indicators table is reproduced in full in Appendix 2

The outcomes and indicators and targets for year 2 are summarised in the tables below.

Outcome 1: Children, young people and adults affected by cleft lip and/or palate are more able to cope with the challenges associated with living with cleft

Output and outcome targets for children and young people

Indicators	TARGETS	
	Numbers of children engaged in Year 2	Number to achieve indicator
Children and young people have increased confidence	78	62 (80%)
Children and young people feel less isolated	78	73 (93%)
Children and young people feel more positive about themselves (positive self-identity)	117	92 (79%)

Output and outcome targets for adults

Indicators	TARGETS	
	Number of adults engaged in Year 2	Number to achieve indicator
Adults have increased confidence	10	6 (60%)
Adults feel less isolated	10	5 (50%)
Adults feel more positive about themselves (positive self-identity)	15	6 (40%)

Outcome 2: Families affected by cleft feel better able to support their child

Output and outcome targets for parents and carers of children affected by cleft

Indicators	TARGETS	
	Number of parents engaged in year 2	Number to achieve indicator
Parents/carers have increased confidence in supporting their child with issues related to cleft	65	50 (77%)
Parents/carers have access to a local support network	65	58 (89%)
Parents/carers feel better able to cope with the challenges associated with cleft	97	79 (81%)

3.1 Children and young people affected by cleft

This section reviews the activities, outputs and outcomes delivered for children and young people in 2018/2019.

Activity days and residential weekends for children and young people with cleft

CLAPA has been successful in raising funding from Children in Need and from Sussex Freemasons which has enabled the RCs to deliver a series of events aimed at providing opportunities for children with cleft to build peer-networks which help to reduce isolation, build confidence, develop a positive self-image and deal with the challenges of living with cleft.

In 2018/19, the RCs have delivered:

- six Activity Days which engaged 48 children and young people,
- two residential weekends for children with cleft – engaging 20 children and young people.



Children having fun at a residential weekend



Children and young people enjoying an adventure day

How many children and young people did CLAPA reach?

Overall there were 122 attendances by children and young people at events, residentials and CYPC meetings over the 12 months from April 2018 to March 2019.

However, the monitoring data shows that many of the children and young people have attended several events/activities: In total, 67 children and young people attended activity days, weekend residentials or CYPC meetings on 2018/2019.

Of those 67 individuals, 35 children and young people attended one event, and 32 of the 67 participants attended more than one events/meeting.

- 18 children and young people attended 2 events
- 7 children and young people attended 3 events
- 5 children and young people attended 4 events
- 2 children and young people attended 5 events

Of the 67 who participated, 33 (around 50%) of them were first time attenders in 2018/19 and 34 had participated in events in the previous year.

Outcomes for children and young people

How does CLAPA gather evidence to demonstrate achievement of indicators?

- We carry out short surveys with and young people about the impact of their involvement in CLAPA events.
- We ask them for examples which can demonstrate the achievement of the indicator
- We ask parents/carers about the impact on their child, through surveys sent to parents/carers after children/young people have participated in a residential weekend.
- The RCs collect informal feedback from parents and carers on the impact of involvement.

Table 2: Outcomes - Targets and actuals (from on surveys with young people)

Indicators	Target Number	*Target %	Actual	Actual %*
Children and young people have increased confidence	62	80%	47	70%
Children and young people feel less isolated	73	93%	61	91%
Children and young people feel more positive about themselves (positive self-identity)	92	79%	62	92%

*The application made an assumption about the percentage of children who engage in activities that would achieve the indicator.

Children and young people provided comments to demonstrate their responses:

Things they felt more confident about

I am more confident about having cleft because I know there are other people like me. Coming to CLAPA event makes me feel more confident because I'm around other people with clefts

I feel more confident being around new people and being seen in public

I have more confidence, and not just with my cleft, with my amniotic bands too

I boost up my confidence every time I come

Sticking up for myself

I can stand up to people

Things they felt more positive about

I feel more positive about being myself

It makes me feel like I'm not different. I'm more normal because I'm around people with the same thing as me. I'm not the only one with a cleft lip (10 year old)

Myself!

Reduced isolation

The most important thing about coming to CLAPA was meeting other people and knowing that I'm not the only person with cleft

That I'm not alone (8 year old)

Some people in the world have cleft – I am not the only one.

Case study

X is 10 years old girl. Her family was first involved in CLAPA when she was a baby. She started coming to Children and Young People's events a couple of years ago After attending a couple of activity days, she then attended a residential weekend. X then decided she wanted to get more involved in CLAPA and in helping other children and young people with cleft and has now joined the Children and Young People's Council. She attended her first meeting of the Council in December 2018.

X has written her own story about her involvement in CLAPA

"My journey with CLAPA started as a baby. CLAPA provided me with all the equipment my mom needed to feed me.

At 3 months old I had a life changing operation. My cleft lip and part of my palate was repaired. At 7 years old I had a bone graft to repair the holes in my palate. During my recovery I became more involved with CLAPA who supported me in a great deal of ways.

When I was younger I was very shy and did not have much self-confidence even though I had many friends. I always knew I was different from others and this upset me.

The more I became involved in CLAPA the more I finally felt self-confidence and realised I am not the only one; and I don't have to be sad about being different. CLAPA has taught me that being different is not horrible or bad it just makes you unique, it is no reason for people to call you names.

For the past few years going to CLAPA events I have realised it is the idyllic place for me."

X's mother commented that going to CLAPA children and young people's events has been really positive for X.

"She has made new friends that she can relate to about having a cleft palate."

"One of X's biggest fears was being bullied for being different. Now she knows she's not the only one with a cleft and she has others to speak to about it."

She says that meeting other children with cleft has had a huge impact on her daughter.

"It makes X feel more positive about herself."

Parents assessment of impact on children.

We also ask parents and carers about the impact on their children of participation in CLAPA events.

Indicators	*Percentage of parents who responded positively
Children and young people have increased confidence	91%
Children and young people feel less isolated	96%
Children and young people feel more positive about themselves (positive self-identity)	100%

*% of parents who responded 'to a great extent' or 'to some extent'. Full breakdown of survey result is included in the Appendix.

Additionally, **91% of parents said that participation in CLAPA helped their child to deal positively with cleft.** This is also demonstrated through the comments received from parents.

E feels less alone and more able to deal with things at school. They have made a massive difference to her.

He's much more confident to talk about why he has a facial scar with others in his day to day life.

His confidence grew over the weekend. He struggles with groups of new children but when he's with CLAPA he is just himself!

She was more confident about having her bone graft after talking to others that had had it done.

Thanks again for yesterday, 'W' absolutely raved about how great it was and feels much more confident about his bone graft after talking to others who had theirs already. He's asked to go to the weekend residential so have just signed him up.

He was able to ask questions about cleft treatment he is yet to undergo, specifically the bone graft and get answers from other children who have already had it.

Being able to observe others who 'look like you' Become friends (or not), discuss cleft (or not) is of real value. My child was particularly pleased to have adult helpers with clefts. They are marvellous role models.

To be able to chat about the challenges - the 'yes that happened to me' conversations reduces feelings of isolation. Parents who don't have clefts can support and empathise but it's not always enough.



Children show their 'Shields' at the end of a residential weekend in September 2018.

Children and staff write positive statements about each other on the shields. Children take the shields home to help them to sustain their self-esteem and to 'ward off' negativity.

"He was very happy to have a shield with good comments about himself from other kids. It gives him energy and supports him" (parent)

Children and Young People's Council (CYPC)

CLAPA also engages children and young people in the CYPC which is aimed at involving children and young people in developing CLAPAs services for children and young people, developing peer-support resources for children and young people, but also to give children and young people a voice in improving cleft services.

There are 15 places on the CYPC. Over 2018/2019, 17 young people have been involved (some of the existing members retired during the year and new members joined).

In the period, CLAPA has delivered:

- A residential team building event in April 2018 attended by 8 children and young people,
- 3 meetings of the CYPC over 2018/19 which have engaged 17 people in total.

In 2018/19, the children and young people on the council have been involved in developing the content on the children and young people's section of the CLAPA website to make the information more accessible and 'young-person friendly'.

They have also been developing new resources aimed at providing support to other children and young people affected by cleft. They have developed:

- A comic book, aimed at children with cleft, which provides 'child-friendly messages about being cleft-positive and not letting cleft hold you back, and providing practical hints and tips about dealing with challenges like bullying.
- A series of videos in which they share their own experiences about a range of cleft related issues. These will be hosted on the CLAPA website and in future there will be an interactive section on the website where young people can ask questions and raise issues. The young people on the CYPC will respond to these by making videos to respond to the issues raised by other young people.

Many of the 'older' young people who have benefitted from being involved in CYPC and receiving peer-support express a strong interest in 'giving back'. They do so in a number of ways:

- **Influencing Services**

The CYPC has been consulted for research proposals and individuals on the CYPC have been involved in training/awareness raising with NHS staff (see case study).

- **Awareness Raising**

Young people from the CYPC also volunteer to deliver awareness raising sessions (see case study).

What do children and young people get out of being involved in the CYPC?

Children and young people develop a range of practical skills through their involvement in the CYPC. In 2018/19, they have taken part in a range of workshops and activities, and have developed skills ranging from beat boxing to comic book design. They have also learned about social media through reviewing the children and young people's section of the CLAPA website.

They have also and provided video clips and short films to use on the CLAPA website earning valuable media and marketing skills as well as building confidence in front of camera and in speaking to the public.

In May 2018, 5 members of the CYPC participated in peer-mentoring training to better understand the role of peer supporters.

As a result of their involvement, they often develop strong peer relationships, but also build their confidence and capacity to deal with their own cleft-related issues.

In a survey of CYPC members after a residential event in 2018,

- 8 out of 8 said that they had met other people they could talk to about cleft (less isolated)
- 8 out of 8 said they felt more confident
- 8 out of 8 said that they felt more positive about dealing with cleft

The survey also showed that the young people were learning from each other

- 5 out of 8 also said that they had learned things about the ways other people deal with having cleft that was useful to them

"I have learnt how to deal with cleft by listening to the way the others deal with cleft. "

"I learnt how others deal with a cleft at school from their positive attitudes about it"

Young people's comments also demonstrate the impact of their involvement on their self-esteem and ability to deal with their own challenges.

"Sharing experiences, Talking openly and proudly about having a cleft. Having fun and being confident within yourself and in the presence of others"

"I can talk about cleft without having to explain it. I can also make a difference (for others) "

The following case studies demonstrate the impact of involvement in the CYPC

Motivation for joining the CYPC

X joined the CYPC in order to meet other people with a cleft and learn about other people's experiences. On a personal level, she wanted to make new friends and become more confident.

Through her involvement in the CYPC, X been involved in making a video, making a comic style information pack for children and has helped to review the young people's section of the CLAPA website.

She is proud of the fact that through her involvement in the CYPC, she has been able to contribute to helping other children and young people with cleft.

Impact of involvement in the CYPC

X says that being in the CYPC has given her a friendship group of people who understand cleft. Having a supportive peer-group has made her feel more positive about her cleft

"CYPC has made me feel better about my cleft because now I can talk to people who can relate to what I'm going through and vice versa."

Her involvement has also increased her confidence, in different ways. X says that she is "more confident about the way I look and about going to hospital appointments" but also recognises that it has increased her social confidence.

"It has also made me more confident as I can talk to people I do not know. And through the CYPC, I have become better at participating in group activities."

"I also want to work as a cleft surgeon when I'm older so it helped me gain valuable knowledge about different clefts."

C is 16 years old and has been involved in the CYPC for two years. C first got involved with the CYPC because she wanted to make difference for other young people with cleft.

"I wanted to help other young people. I wanted to hear about other people's experiences and I wanted to make a difference to the CLAPA community."

She says that what she has enjoyed most about being in the CYPC is meeting other young people with cleft, but she also feels like she has made a contribution to helping others. One of her biggest achievements was doing a speech to 70 leading surgeons and nurses about her cleft journey (at a training event for NHS staff).

"I talked about my life since the day I was born, I talked hospital experiences and life with a cleft, such as hearing problems which originate from having a cleft. I loved doing this speech and it gave me a chance to look at my cleft and research more into my own condition."

C says that being involved in the CYPC has built her confidence and made her more positive about herself. She also says that she has become "more confident in talking about my cleft."

Last month C gave delivered an awareness raising talk at a full school assembly at her school.

"It was so brilliant to be able to raise awareness to my WHOLE school about cleft lip and palate and the amazing charities that support us"



Well done, C [redacted] ★

[redacted] High School @ [redacted]
[redacted] leads our assembly this morning on the amazing work of @CLAPACOMMUNITY supporting and empowering people with cleft lip and palate



At the personal level, being involved in the CYPC has helped C to feel less isolated, and improved her self-confidence and self-esteem.

"The CYPC made me feel less alone and more happy with what I look like."

Conclusions and learning

Outputs against targets

The target was to engage 117 children and young people in year 2.

- There were 122 attendances by children and young people our activities and residential events there were
- However, our monitoring data shows that we engaged 67 children and young people, and that nearly half of those (32 of the 67) attended multiple events/activities.
- As a result, the number of children and young people who have engaged in activities is lower than the target for Year 2.

Indicators	Target	Actual
Children and young people have increased confidence	78	67
Children and young people feel less isolated	78	67
Children and young people feel more positive about themselves (positive self-identity)	117	67

The importance of repeat attendances.

CLAPA has improved its monitoring processes in 2018 and now tracks not just the number of attendances at events but also the individuals who attends each session. The tracking system shows a pattern of multiple attendances at events. The data and the feedback from children and young people and their parents tell us that children benefit enormously from attending the events/activities. However, although the activity is the hook – the importance of the events are that they provide opportunities for children and young people to meet others with cleft, to realise that they are 'not the only one' and to share their experiences with other children who understand that element so their life-experience. For many children, it has been repeat attendance which have enabled them to build confidence and develop supportive peer-relationships.

The case study below demonstrates how attending several events has helped a young person to develop a positive peer-group which has contributed to building confidence, reducing isolation and building positive self-identity.

E is an 8 year old girl. Her mother is was a volunteer for CLAPA and E attended a fundraising event with her family when she was 5 years old.

When E was old enough to attend Activity Days, her mother suggested she come to an activity day to meet other children with cleft. E attended her first children's activity day in 2018.

E's mother said "The day came just at the right time for E as she's been feeling quite self-conscious about her cleft. Meeting the other children today made her feel much more positive."

E was keen to meet with more children with cleft and to hear about their experiences, so her mother signed her up for a residential event in September 2018.

E said that although she knew there were other people in the world with clefts, she didn't know many people. She said the best thing about the residential was making new friends and having people to talk to about having a cleft - **"people who understand about cleft and the operations."** She says that hearing about other people's experiences, in particular the surgeries, makes her more confident about her cleft and her own forthcoming operations.

E is keen to develop her network of people who understand about cleft. She attended her third event January 2019. Her mum says that each event helps to build E's confidence.

Her mum wrote: "Thank you so much for running such a wonderful activity day today. E came home buzzing, declaring "it was the best day ever!". She loved it all!

"We really appreciate the time and effort that goes into organising these events and we're always thrilled when E returns that little bit more confident."

Outcomes V targets

As the numbers of children and young people engaged in year 2 is lower than the target number, the number achieving each outcomes indicator is also lower than the target. Table XX shows the percentage of those engaged who achieved the indicator.

- 70% of children and young people reported that they felt more confident. This is below the target of 80%.
 - It would appear that some of the children and young people do not connect with a feeling of lack of confidence, as demonstrated by comments from those who score this indicator as 'neutral' or 'disagree'.

"I have always been confident"

- 91% achieved indicator 2 (reduced isolation) which is in line with the target (93%)
- 92% achieved indicator 3 (feeling more positive about themselves) against a target of 79%.

Indicators	Outcome Target	Actual
Children and young people have increased confidence	62	47
Children and young people feel less isolated	73	61
Children and young people feel more positive about themselves (positive self-identity)	92	62

Indicators	Outcome Target	Actual
Children and young people have increased confidence	80%	70%
Children and young people feel less isolated	93%	91%
Children and young people feel more positive about themselves (positive self identity)	79%	92%

It is interesting to note that parents scored the impact of involvement on their children more highly than the children. 91% of parents also said that participation in CLAPA helped their child to deal positively with cleft.

Indicators	% of children who reported positively	% of parents who responded positively
Children and young people have increased confidence	70%	91%
Children and young people feel less isolated	91%	96%
Children and young people feel more positive about themselves (positive self identity)	92%	100%

Events for older teenagers

Children and young people's events are aimed at children from 8 to 15 years old. However, feedback from young people and parents tells us that teenagers (13 and upwards) do not want to attend events with 8 year olds, and that the opportunities for developing peer-relationships are more effective among groups of similar ages. We will pilot some 'teenager only' events next year to respond to the feedback from the young people. The first event is planned for August 2019.

3.2 Adults

Activities and outputs

The activities aimed at supporting adults with cleft are:

- **Peer support service**

28 adults have received peer support through the volunteer peer support service.

- The England RC's have matched 28 adults with trained volunteers (adults with a cleft) through CLAPA's Peer Support Service.
- Adults sought help and support around a range of issues :surgery, feelings of isolation, requests for information about psychological support, concerns with speech, appearance, delayed diagnosis, access to information, and decisions around becoming a parent.

- **Roadshows**

RCs have worked with CLAPAs new Adult Services Co-ordinator to engage with adults within their regions through a series of roadshows. This has resulted in engaging new adults in each Region and re-engaging with adults who have had a previous involvement with CLAPA. As a result, the RCs have engaged/re-engaged with 30 adults:

- Central – 6 adults
- East – 8 adults
- South East – 16 adults

Numbers of adults engaged in 2018/2019

Because of the additional activity which CLAPA has delivered around the development of adult services (the roadshows), the number of adults who engaged in 2018/19 is significantly higher than the target.

Activities	Numbers engaged in 2018/2019	Target number of adults engaged
Adult engagement roadshows	30 adults	10
Peer Support Service	28 adults	

Outcomes for adults

The survey results demonstrate that over 90% of adults with cleft increase confidence, reduce feelings of isolation and improve their self-esteem through involvement in CLAPA.

Indicators	Year 2 targets for adults	Number of adults engaged in period	Results from survey
Adults have increased confidence	10	58	<ul style="list-style-type: none"> just under 90% reported that they had increased confidence
Adults feel less isolated	10	58	<ul style="list-style-type: none"> 95% reported that they felt less isolated
Adults feel more positive about themselves (positive self- identity)	15	58	<ul style="list-style-type: none"> 95% reported that they felt more positive about themselves

NB these results are based on survey results from a survey of adults engaged through events. Although we ask individuals to provide evaluation feedback from the peer support services, the number of people who complete the survey is very small.

Qualitative evidence from Adults

Many of the comments from adults related to 'feeling less isolated' and the benefit of peer-support in terms of gaining access to information and emotional support.

Reduced isolation

- *Meeting others – finding more info. Realising some things don't only happen to me – others have had conditions/problems that I have had which is reassuring.*
- *I've realised how important it is to have a support network.*
- *Meeting others and sharing experiences. Feeling supported and accepted.*
- *Hearing others experience knowing I'm not alone.*
- *Realising I am not alone. Knowing the NHS cleft team is there if I ever need it.*
- *Enjoyed being around people with CLP as have never previously had opportunity.*
- *Information – I have been able to ask all questions that I can think of without fear of judgment. I have been put in contact with the correct people*

Conclusions and learning

The number of people engaged through the adult engagement events and through the Peer Support Service has exceeded the target for year 2 and highlights the level of need for support among adults with cleft.

Adult volunteers (volunteers who are adults with cleft)

Many of CLAPAs volunteers are adults with cleft. Although adults with cleft often involved in volunteering to 'give back' to the cleft community, the quotes taken from evaluation forms demonstrates the impact of volunteering on their confidence, self-esteem and capacity to cope with their own cleft-related issues.

Adults with cleft are involved in volunteering in a number of roles:

- on Patient Voices Groups
- as Peer supporters

- Adults with cleft who volunteer to support delivery of children and young people's events

Evidence from evaluation forms includes:

"I have met other adults with clefts which has helped me. Having shared experience and coping mechanisms helps in my daily life.

"Having a group that I know and trust where I can talk about my cleft issues is of real help to me. That is further aided by the facebook group where on many occasions issues I had learnt to cope with are shared by others and I have been able to learn from them or give them help."
(Adult volunteer involved in Patient Voices Group)

"I have met so many people, who are now friends, that can relate to problems and issues that I have that none of my 'normal' friends or family can relate to." Adult volunteer (adult with cleft)

"Volunteering for residential weekends allows me to help others affected by cleft. Working with Children and young people allows me to help them become more confident and feel that having a cleft isn't necessarily negative. This in turn helps me by knowing I have positively affected others' lives. Additionally, it has helped me learn to take on responsibility and become more confident when speak to groups of people. (adult with cleft who volunteers at children/young people events)

3.3 Parents and families

Activities and outputs

CLAPA delivers a range of events and services for parents and families through its volunteers. The activities/events/services include:

- Family events
- Happy Faces Groups
- Parent Support service
- On-line Networking.

Family events

Family events take a number of forms: they can be summer picnics, Christmas parties or fundraising events. Most are organised and delivered by groups of volunteers. They provide opportunities for parents and families to meet other families affected by cleft in an informal setting and develop supportive peer relationships. In some areas where there are fewer volunteer event groups, RCs deliver family events.

Happy Faces Groups

These are volunteer led groups which provide peer-support for new parents of children born with cleft.

There are five Happy Faces Groups in Central Region and two in East Region. The Happy Faces Groups are co-ordinated by local volunteers so the frequency and type of activity varies depending on the interests/capacity of the volunteers. Groups meet throughout the year and provide opportunities for families who attend to build strong supportive relationships.

In Central Region, Cleft Nurses from the local Cleft Team often attend Happy Faces Groups, so the groups also provide parents with access to medical advice in an informal setting.

In 2018/2019, 65 families have been supported through volunteer led Happy Faces Groups.

Parents comments about the Happy Faces Groups:

"Our local happy faces group is a true treasure. It is amazing to have a group of parents in a similar situation to chat to and the support is beyond amazing"

"It was really nice to meet other mums who have been through similar situations and who understood what my family have been through."

Parent and Peer Support Service

In 2018/19, CLAPA received Approved Provider standard APS standard for its Parent and Peer Support Service. The Approved Provider Standard is a national quality mark designed specifically for mentoring and befriending projects. Achieving the standard demonstrates that the project met the 10 requirements of the standard, and was independently assessed by experts in good practice in mentoring, befriending and peer support.

In 2018/2019, 49 Parents have received support through the Parent Support Services. Some examples of feedback from parents

"Really glad I did it [the Parent supporter] has really assured my family and I at a time when most needed. I feel much more positive."

"I feel less isolated and better able to deal with the issue I contacted about and I feel much more positive"

On-line networking

We use multiple on-line platforms to provide information, share news, updates and events to connect the community.

- The national Facebook group has 14,500 members.

We have also set up closed Facebook Groups for people in each region, to enable people in the local groups to contact each other and to provide mutual support. The local Facebook groups have been very successful.

- In Central Region, there are eight Facebook groups with 823 members (some people may be on more than one group). The Groups are aimed at parents and families of people affected by cleft but often include extended family and friends and of people affected by cleft.
- In East region there are four Facebook groups with 593 members
- In South East, there are seven groups with 878 members
- We have also recently started a volunteer Facebook group to connect to volunteers and give them a platform to engage with each other

Not every person on the group is a parent of a child with cleft – the group is open to friends, families and other supporters, and some people will be on more than one group, but the numbers who engage through Facebook groups has exceeded our expectations.

Outcomes

The outcome data, collected through bi-annual survey, demonstrates that over 90% of parents feel that they have access to a support network, that they have increased confidence in supporting their child, and that they are better able to cope with the challenges associated with cleft.

Indicators	Target number to achieve indicator	% expected to achieve indicator	Number of parents/families engaged	% achieving indicator
Parents/carers have increased confidence in supporting their child with issues related to cleft	50	77%	*252 families engaged in family events etc	95%
Parents/carers have access to a local support network	58	89%	65 families supported through HFGs)	96%
Parents/carers feel better able to cope with the challenges associated with cleft	79	81%	49 parents received support from parent support service	92%

*This number represents the number of families who have attended events and will contain some double counting as some families have attended more than one event.

What do parents tell us about the impact of being involved in CLAPA?

I think it is hugely beneficial to be able to meet other cleft families. It provides me with people to talk to who are going through similar situations. It also allows me to know what to expect when I am worried about the future and treatment my child may need.

It makes us feel less isolated with the issues we face as others understand what we are talking about.

The events put on by CLAPA are so vital to connecting likeminded families. For children and their families to meet and share real life experiences. You simply can't put a price on what it gives to families going through challenging times.

Talking to people who "get it" is invaluable and so refreshing. Also for my son to see others with hearing aids or other similarities is so helpful in him understanding his identity and feeling normal.

it's amazing to have a community to meet up with; same thing we all have in common. Meeting other parents and children gives us encouragement that all will be ok. It's also good to support others who are newer to the journey. thanks very much

Myself and my partner now feel that (thanks to CLAPA) we are part of a community as opposed to feeling isolated and alone in our experiences of cleft, our worries and concerns for the future.

Thanks to CLAPA we are able to access support networks of other parents through the Facebook page, CLAPA events and parent support volunteers. We

have learned about positive attitudes, answers to give to cleft related questions from others and our child, resources such as books that will help us to support our child to understand her condition and feel more positive about it. This has been really vital to our wellbeing and in turn, our ability to be supportive to our daughter who was born with cleft.

For our daughter we hope that meeting other children with cleft will help to normalise it and CLAPA events like the young people's residential will support her resilience and ability to develop strategies to help deal with any anxiety around her condition that may arise as she grows up. She will hopefully have a support network of children / young people too.

All in all getting involved with CLAPA has been invaluable!

Conclusions and learning

The RC project has outstripped the target for number of parents/families engaged on 2018/2019.

The anticipated number of parents/families engaged in 2018/2019 was 97. The number of families engaged through the different activities is shown in the table below.

Activity	Number of families engaged in 2018/2019
Family events	252*
Happy Faces Groups	65
Parent Support Service	49

*This number represents the number of families who have attended events and will contain some double counting as some families have attended more than one event.

It is important to note that parents and families have different levels of engagement: Many of the activities delivered for parents and families are relatively light touch, for example family fun days, fundraising events, Christmas parties. Some families have come along to one only event while others have very high levels of engagement with CLAPA through multiple events, active engagement in the Facebook Groups, and some parents are also volunteers.

Other services provide a much more intensive level of engagement:

- the Parent Support Service provides one-to-one support from a volunteer
- some of the Happy Faces Groups provide monthly 'meet-ups' for parents of babies/children.

Outcomes for parents and families

The outcomes evidence is drawn from a bi-annual parent survey. Survey respondents have a very mixed level of engagement, but the evidence suggest that over 90% of parents have achieved each of the indicators.

We recognise that there is an element of respondent bias (those who have benefited from support are more likely to respond to the survey), but the finding demonstrate that access to peer-support networks (even relatively light-touch engagement) is significant in supporting parents of children with cleft.

The impact of light touch interventions

Our evaluation evidence suggests that families with a higher level of intensity of engagement gain the most from their involvement. However, the impact of even 'one-

off' participation in events can provide access to peer support from families as demonstrated in the stories below.

A group of parents of children with Pierre Robin Sequence (a particular syndromic condition with a cleft palate) were introduced to each other by a volunteer at a CLAPA Christmas party. The parents set up a 'Whatsapp' group and keep in touch and provide informal peer-support for each other.

From a parent who attends annual Christmas events

It has been a great help understanding and accepting my daughters cleft lip. We first took her to her first CLAPA Christmas party at 6 months old before her first operation and as soon as I saw other children and parents who have been through what I was about to go through I can't describe how helpful and supportive it was.

We have been attending them ever since, my daughter is now 5 and it is nice for her to be able to be around children who are similar to her.

The power of social media

We initially started to use Facebook as mechanism to keep in contact with our volunteers and supporters in the regions and inform them about events etc. However, we have been surprised by the growth in the numbers of people involved in the Facebook groups but also by the type of use of the Facebook group. Members frequently pose questions and concerns of the Facebook Group and received advice and peer support from other members.

Appendix 1: Revised outcomes and indicators

Revised Outcomes	Revised Indicators	When ?	South East		East		Central		TOTAL REACHING INDICATORS ACROSS 3 REGIONS
			TOTAL	REACH INDICATOR	TOTAL	REACH INDICATOR	TOTAL	REACH INDICATOR	
Outcome 1 Children, young people and adults affected by cleft lip and/or palate are more able to cope with the challenges associated with living with cleft	Children, young people and adults have increased confidence	Year 1, Year 2, and Year 3	C&YP: 75 Adults:10	C&YP: 60 Adults: 6	C&YP: 75 Adults:10	C&YP: 60 Adults: 6	C&YP: 85 Adults: 10	C&YP: 67 Adults: 6	C&YP: 187 (out of 235) Adults: 18 (out of 30) TOTAL: 205
	Children, young people and adults feel less isolated	Year 1, Year 2, and Year 3	C&YP: 75 Adults: 10	C&YP: 70 Adults: 5	C&YP: 75 Adults: 10	C&YP: 70 Adults: 5	C&YP: 85 Adults: 10	C&YP: 79 Adults: 5	C&YP: 219 (out of 235) Adults: 15 (out of 30) TOTAL: 234
	Children, young people and adults feel more positive about themselves (positive self identity)	By the end of the project	C&YP: 112 Adults: 15	C&YP: 88 Adults: 6	C&YP: 112 Adults: 15	C&YP: 88 Adults: 6	C&YP: 127 Adults: 15	C&YP: 100 Adults: 6	C&YP: 276 (out of 351) Adults: 18 (out of 45) TOTAL: 294
Outcome 2 Families affected by cleft feel better able to support	Parents/care rs have increased confidence in supporting their child	Year 1, Year 2, and Year	Parents / guardians: 65	Parents/ guardians: 50	Parents / guardians: 65	Parents/ guardians: 50	Parents / guardians: 65	Parents/ guardians: 50	Parents/ guardians: 150 (out of 195) TOTAL: 150

their child	with issues related to cleft	3							
	Parents/careers have access to a local support network	Year 1, Year 2, and Year 3	Parents / guardians: 65	Parents/ guardians: 58	Parents / guardians: 65	Parents/ guardians: 58	Parents / guardians: 65	Parents/ guardians: 58	Parents/ guardians: 174 (out of 195) TOTAL: 174
	Parents/careers feel better able to cope with the challenges associated with cleft	By the end of the project	Parents/ guardians: 97	Parents/ guardians: 79	Parents/ guardians: 97	Parents/ guardians: 79	Parents/ guardians: 97	Parents/ guardians: 79	Parents/ guardians: 237 (out of 291) TOTAL: 237