Evaluation of CLAPA's Regional Coordinators Project

Project ID: 0010287887

CLAPA Cleft Lip & Palate Association

Evaluation of CLAPA's Regional Coordinators Project

May 2020

Arrivo Consulting Ltd
7 Montgomery Street Lane
Edinburgh
EH5 7JT
fiona@arrivoconsulting.co.uk

Contents

Executive summary

The project provides activities for children and adults born with cleft lip and/or palate (cleft) and for families affected by cleft to meet and provide informal peer support. The project's purpose is to enable them to better deal with the challenges associated with living with a cleft.

The RC Project employs Regional Coordinators in each of three regions of England (East, Central and South East). Much of the activity of the RC Project is delivered through a network of volunteers.

The project has benefited from the input of around 100 volunteers each year.

Activities and outputs

The RC project delivers activities for:

- children and young people born with a cleft
- adults born with a cleft
- parents and families of children born with a cleft

The delivery model is explained in the infographics.

Diagram 1 shows activity and outputs for parents/families of children born with a cleft and adults born with a cleft (data is for Year 3 of project delivery).

Diagram 2 (page 3) summarises the activity and outputs for children and young people.

Diagram 1: Activity and outputs for parents and families and for adults born with cleft

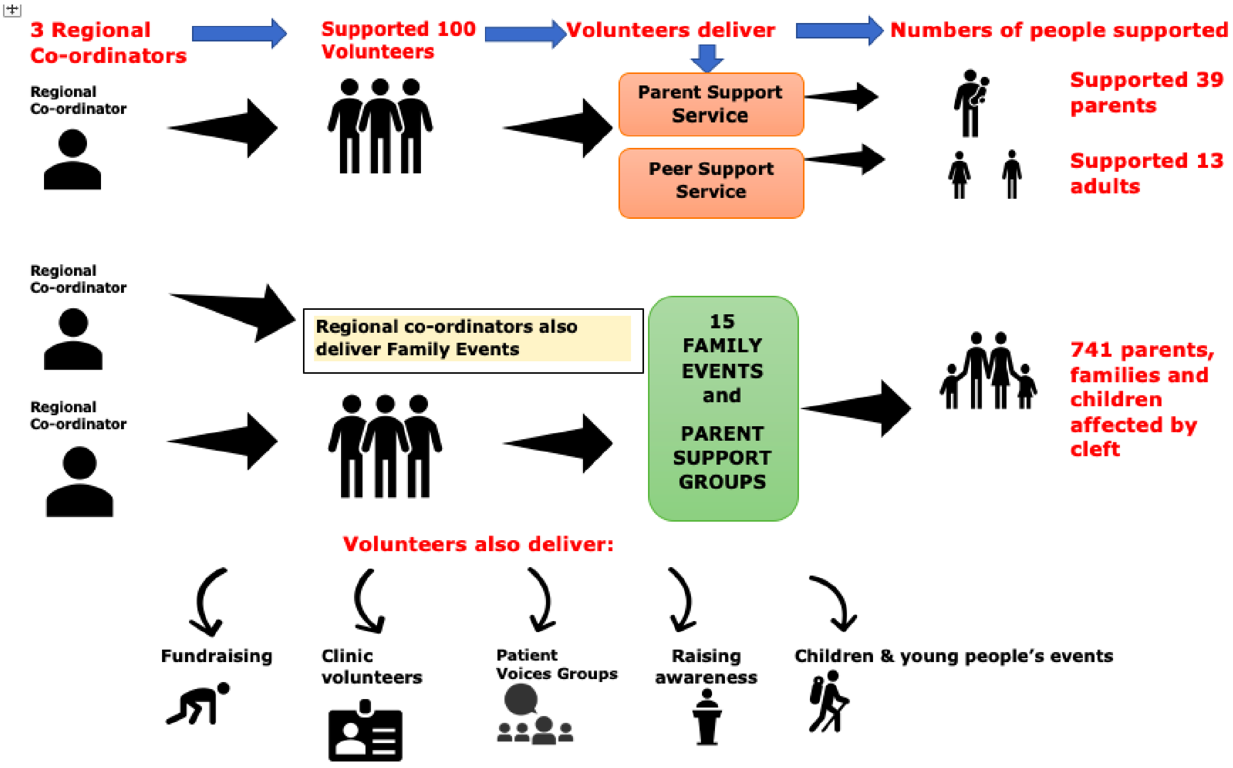
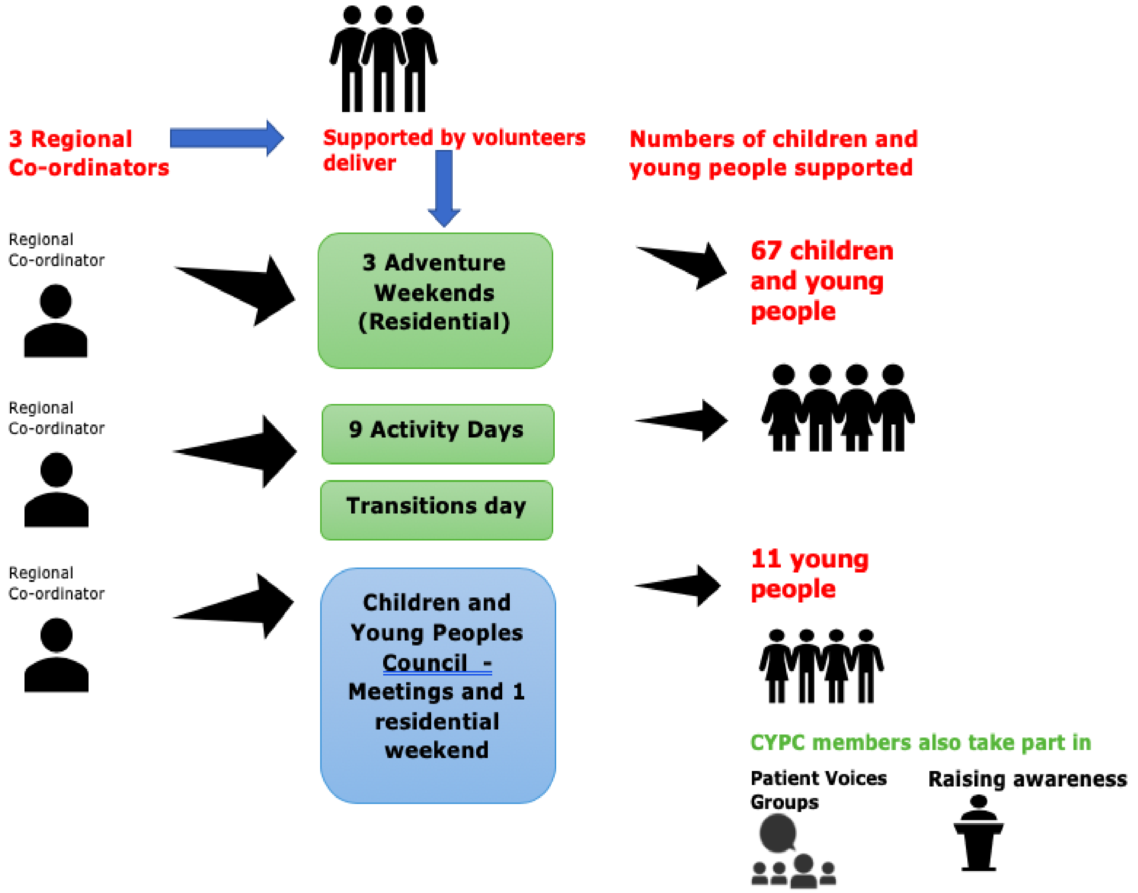


Diagram 2: Activity and outputs for children and young people (Year 3 data)



Outcomes

The project has two key outcomes:

- **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**
- **OUTCOME 2: Families affected by cleft feel better able to support their child**

The table on page 4 summarises the achievements of these outcomes against its targets.

Outcomes against targets

Outcomes (revised at end of Yr. 1)	**Indicators** (revised at end Yr. 1)	Number of participants **Target**	Number of participants **Actual**	Percentage achieving this indicator **Target**	Percentage achieving indicator **Actual**		
					Yr1	**Yr. 2**	**Yr. 3**
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	C&YP: 235	335 attendances 139 individuals	80% (187)	*N/A	70 %	80%
		Adults: 30	47 Peer Support 30 in Roadshows	18	*N/A	90%	*N/A
	Children, young people and adults feel less isolated	C&YP: 235	335 attendances 139 individuals	93% (219)	*N/A	91%	89%
		Adults: 30	47 in Peer Support 30 in Roadshows	15 (50%)	*N/A	95%	*N/A
	Children, young people and adults feel more positive about themselves (positive self-identity)	C&YP: 351	335 attendances 139 individuals	79% (276)	*N/A	92%	90%
		Adults:45	47 in Peer Support 30 in Roadshows	18 (40%)	*N/A	95%	*N/A
Outcome 2 Families affected by cleft feel better able to support their child	Parents/carers have increased confidence in supporting their child with issues related to cleft	195	Approximately 800 parents and family members engaged in family events and groups each year. 119 supported through Parent Support Service over 3 years	77% (150)	94%	95%	94%
	Parents/carers have access to a local support network	195		89% (174)		96%	91%
	Parents/carers feel better able to cope with the challenges associated with cleft	291		81% (237)	94%	92%	94%

Has the project delivered the expected outcomes?

Children and young people

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

The project target was to engage 351 children and young people over the life of the project.

- There were 335 attendances by children and young people
- The number of unique individuals who have been engaged over the three years of the RC project is 139.

While the RC Project has engaged fewer children and young people than anticipated, the data shows that the project has achieved a deeper level of engagement with a smaller number of children and young people.

- 71 of the 139 children and young people (over half) have attended two or more events

Data from evaluation carried out in Year 2 (2018/19) and Year 3 (2019/20) demonstrates that the RC Project has been successful in supporting children and young people to achieve this outcome:

- The evaluation feedback from children and their parents demonstrates that the project has reduced isolation, built confidence and a sense of positive self-identity for nearly 90% of children and young people who attended events.

- Young people who had benefited from a more intense level of engagement (those who attended multiple events) could also identify how the impact of their involvement carried over into other aspects of their lives.

These findings suggest that any future model of support should provide opportunities for longer-term sustained engagement rather than one-off interventions to maximise the impact for children and young people.

Adults born with cleft

Adults affected by cleft lip and/or palate are more able to cope with the challenges associated with living with cleft

The target was to engage 45 adults born with a cleft. The project provided support for 47 adults born with a cleft through the Peer Support Service. Little formal evaluation evidence is available from this service but comments from users suggest that the Service has provided access to advice and emotional support which helped users to cope with challenges.

A further 30 adults were engaged through Road Shows in Year 2. Evaluations from those adults identified that:

- just under 90% reported that they had increased confidence as a result of engaging with CLAPA
- 95% reported that they felt less isolated
- 95% reported that they felt more positive about themselves

Parents and families

The project target was to reach 291 parents/families over the life of the project.

The project has exceeded this target by a significant margin:

- 119 parents have been supported through the Parent Support Service
- Around 800 parents and family members have been engaged in peer-networking events each year.

The project outcome in relation to parents and families is:
Families affected by cleft feel better able to support their child

While engagement in activities/events can be relatively light touch (for example, attending annual Christmas events) the RC Project has been successful in creating access to a 'community' and the evaluation evidence demonstrates that around 90% of parents report that they feel 'better able to support their child' as a result of their involvement in CLAPA.

Other outcomes: from the RC Project

- **Raising awareness of cleft and influencing services**

Alongside the direct delivery of activities aimed at supporting children and families, the Project has also been successful in supporting people affected by cleft to raise awareness of the needs of cleft patients and influence services for cleft patients.

- **Outcomes for volunteers**

The evaluation also highlighted that many volunteers developed skills and experience which were valuable in other areas of their life.

- 85% said that they had gained skills and experience through volunteering which were useful in other areas of their life.

Learning from the delivery model

A key strength in the project design is the creation of volunteer led peer networks which provide families affected by cleft with access to a 'community' which provides practical and emotional support.

Critical success factors in the delivery of the model

The number /capacity of volunteers
The level of activity and the outcomes delivered by the RC Project are impressive. The project employed only three staff but has mobilised over 100 volunteers each year to deliver activities and events which have engaged hundreds of parents and families. The success of the project has in this respect has been the result of the achievements of the Regional Coordinators in recruiting and supporting volunteers.

The Regional Coordinator role
While volunteers have been central to the delivery of the project, the Regional Coordinator role is the critical component in the model.

- In year 3, (2019-20) volunteers provided over 600 hours of time in the delivery of services for children and families affected by cleft which supported nearly 800 parents, siblings and family members.
- However, as demonstrated during the staff vacancy in the East of England Region in Year 1, the level of activity was significantly reduced in the period when volunteers did not have support, and some volunteers gave up their volunteering role in this period.

This highlights the critical role of the RC in the delivery model. The Regional Coordinators are the lynchpin in the delivery model, without which CLAPA could not mobilise the enormous volunteer effort.

Levering additional funding to deliver events for children and young people
The Project has also been successful in levering additional funding from other funders which has enabled it to deliver targeted events for children and young people aged 8-18. This has increased the impact of the project (improved outcomes for children and young people) and improved the 'value for money' for core funders.

Use of social media (Online networking)

While the delivery of events which bring families together have been central to the creation of peer networks and to the success of the model, the RC Project has also maximised the use of social media to extend the reach and depth of peer support networks.

- Facebook Groups have become virtual peer support networks, with users frequently commenting that they provide 24/7 access to 'advice and support from other people who are further along the cleft journey'.
- Additionally, people from more rural and remote areas who have more difficulty in getting to events have commented that the Facebook Groups allows them to participate in the 'cleft community'.

Challenges in the delivery model

Different levels of activity in different regions

The number of events and types of events which have been delivered in each region have varied considerably because delivery is volunteer-led and therefore dependant on the number of volunteers and the skills and interests of those volunteers. For example:

- in the Central Region, volunteers delivered parent support groups (previously known as Happy Faces Groups) but there were no Happy Faces Groups in the South East Region
- Volunteers in the South East Region delivered more family days and events which have engaged large numbers of families but provide a less intensive level of support.

The differences in the delivery infrastructure (number of volunteers and volunteer interest and capacity) has posed challenges for the project in terms of planning and setting targets for engagement.

Challenges in engaging and supporting volunteers

Volunteers have been central to delivery of peer networks and events, and while CLAPA has a number of very long-term and experienced volunteers, the project has, at times, struggled to recruit new volunteers and has struggled to engage volunteers in formal training days.

- Feedback from volunteers highlighted that volunteers were often 'busy people' (work and family commitments) and found it difficult to give up their weekends to attend training.

Addressing the challenges

The RC Project has been responsive and innovative in response to the challenges of recruiting and supporting volunteers.

- **Review of volunteering structures/increasing flexibility for volunteers**

Regional Coordinators found that many people were interested in 'giving something back to CLAPA', but that people were less interested in engaging in the formal governance structures and wanted more flexibility in their volunteering commitment.

The RC's developed more flexible structures which are less bureaucratic and enable volunteers to engage in a different way – there are events groups for those volunteers who are interested in delivering events, but also more flexibility to provide opportunities for people to volunteer in one-off occasions (helping at events, etc).
The review of volunteering structures by the RCs has influenced CLAPA structures /engagement with local groups at a national level.

- **Review of recruitment**

The challenges in recruiting volunteers and matching volunteers to delivery roles resulted in changes in the volunteer recruitment practices. At the end of year 2, the RCs piloted a more targeted recruitment campaign, focusing on recruitment of volunteers with specific skills or experience to fill specific roles (e.g. recruitment of parent supporters with lived experience of specific conditions). This proved successful in increasing the number of volunteers and the 'fit' of volunteers.

- **Review of volunteer training /increasing accessibility of training**

In light of the challenges in getting volunteers to attend face-to-face training (due to the time pressure on volunteers) the RC Project has developed alternative methods to make training more accessible to volunteers including online training and one-to-one training by RCs. The Project also piloted shared training with another charity (Rett UK) to cut the overhead costs of training delivery.

These developments have not only benefited the RC Project but have influenced the approach to volunteer training and development within the whole organisation.

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 three-year grant from the Big Lottery Fund for its Regional Coordinators Project. The funding enables CLAPA to employ three Coordinators (based in three different regions of England) who recruit and support volunteers to deliver activities which support families, children and adults affected by cleft.

Purpose of the report

The Regional Coordinators (RC) Project has now completed its three years of operation. This report reviews the activities and outcomes delivered over the life of the project. The report provides:

- a summary of the project model: how the project delivers activities and outcomes
- a review of the achievements over the three years and comment on the extent to which the project has achieved its target outputs and outcomes,
- the learning from the project.

Methodology

CLAPA commissioned an external consultant, Arrivo Consulting Ltd to develop an evaluation framework and tools to enable CLAPA to measure the outcomes of its activities. These tools have been used over the life of the project to collect evaluation data.

Evaluation data is collected from people who participate in CLAPA activities through a variety of methods:

- children and young people who attend activities complete short surveys to report on the impact of their involvement.
- parents of children and young people comment on the impact on their children through online surveys
- parents and families who engage in family events, groups and through the on-line networks are surveyed annually.

The external evaluator has also:

- developed case studies to demonstrate how CLAPA has supported the achievement of outcomes for individuals,
- collected feedback from NHS Cleft Teams who can comment on the need for the Project and the impact of on children and families affected by cleft.

Evaluation issues

Changes to project outcomes and indicators

The outcomes and indicators for the RC Project were reviewed as a result of learning from the evaluation of Year 1. Revised outcomes and indicators were agreed with the Big Lottery Fund (now known as the National Lottery Community Fund) at the start of year 2 of the Project.

The RC Project has two key outcomes. Each outcome has three indicators. The significant changes in outcomes and indicators were:

OUTCOME 1: The outcome statement remains the same, but all of the three indicators have been amended. The key changes are to the indicators for outcome 1 as shown in the table below. As a result of the change in indicators, the evaluation data collected in Year 1 of the project is not comparable with data collected in Years 2 and 3.

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		
Indicator 1: Children, young people (C&YP) and adults report increased knowledge of mechanisms for coping with cleft-related challenges	became	Indicator 1: Children, young people and adults have increased confidence
Indicator 2: Children, young people and adults report having access to a local support network	became	Indicator 2: Children, young people and adults feel less isolated
Indicator 3: Children, young people and adults report being more able to cope with cleft-related challenges	became	Indicator 3: Children, young people and adults feel more positive about themselves (more positive self-identity)

As the indicators have been revised significantly, evaluation data collected in Year 1 is not comparable with data collected in Years 2 and 3.

OUTCOME 2: The outcomes statement was amended for greater clarity, but the indicators remained substantively unchanged. As the indicators remained the same over the life of the project, the evaluation data can be compared over the life of the project

Original outcome 2	Parents/guardians of child(ren) with cleft feel less isolated, more able to cope and more able to support their children
Amended outcome 2	Families affected by cleft feel better able to support their child

For information, the revised project outcomes are included at Appendix 1.

Impact of the COVID-19 pandemic

The COVID-19 pandemic has affected the delivery of the project in the final months of operation.

- All scheduled events and activities were cancelled from early March 2020. As a result, the number of activities and outputs for year 3 of the project has been reduced, affecting the achievement targets in year 3 of the project.

Report structure

The report structure is as follows:

Chapter 2:	This chapter provides an overview of the delivery model: the role of the Regional Coordinators and volunteers in the delivery of activities.
Chapter 3:	This chapter describes the activities delivered to engage children and young people and reports on the outcomes achieved.

Chapter 4: This chapter reports on the activities and outcomes for adults born with a cleft.

Chapter 5: This chapter reports on the activities and outcomes for parents and families of children born with a cleft.

Chapter 6: This chapter provides a summary of the wider outcomes and impact of the RC Project.

Chapter 7: This chapter provides conclusions on the findings of the evaluation and summarises the learning from the project.

2. Overview of the Regional Coordinators Project

Why is the project needed?

Cleft lip and/or palate is a common birth condition that can affect a number of functions including feeding, speech and hearing. Children's dental and psychosocial health may also be affected.

Surgery usually takes place in the first year of life. Children may have further surgery to improve their appearance and function as they grow. Other non-surgical help and support such as speech therapy, hearing support and psychological support may also be needed by some children.

Typically, children with a cleft lip and/or palate need cleft team care from birth to adulthood.

Extract from CRANE Annual report on Children with Cleft lip and/or palate, CRANE Database, Cleft Audit and Registry Network, 2017

Although cleft is the most common birth condition, affecting around one in 700 births in the UK, many families affected by cleft do not know anyone else with the condition.

Children can grow up feeling isolated: the most common feedback from children in response to the question 'What's the most important thing for you about coming to CLAPA events was 'knowing that I'm not the only one with a cleft'.

Parents of children with a cleft can also feel isolated as they frequently don't know other parents who understand their fears and concerns or who can provide advice and support. Parents frequently tell us that they get so much from meeting other parents who 'understand what we are going through'.

Purpose of the project

The purpose of the Regional Coordinators project is to support people - children born with a cleft, parents and families of children with a cleft and adults born with a cleft – to better cope with the challenges of living with a cleft.

The project has two key outcomes:

- **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**

- **OUTCOME 2: Families affected by cleft feel better able to support their child**

The RC Project employs Regional Coordinators in each of three regions of England (East, Central and South East). The project supports the delivery of activities in each of the three regions aimed at:

- children and young people born with a cleft,
- parents and families of children born with a cleft,
- adults born with a cleft.

The activities focus on providing opportunities for children and families affected by cleft to meet and provide informal peer support.

Much of the activity of the RC Project 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.

The project has benefited from the input of around 100 volunteers each year.

	YEAR 1	YEAR 2	YEAR 3
Number of volunteers	109	116	100

What do volunteers do?

Volunteers are at the heart of the RC Project and are key to the development and delivery of activities and services to support families affected by cleft. This section summarises the types of activities delivered by volunteers aimed at families affected by cleft.

Events Groups: Local groups of volunteers organise and deliver local events for parents and families. These include Family days, summer picnics, Christmas get-togethers, etc. These events provide opportunities for whole families affected by cleft to meet other families in an informal setting and share experiences and develop supportive peer relationships. Some events groups organise fundraising events and awareness raising events proving further opportunities for families and children to get together in informal settings.

Parent Support Groups: These are volunteer led groups in local areas that provide peer-support for parents of children born with cleft (previously known as Happy Faces Groups).

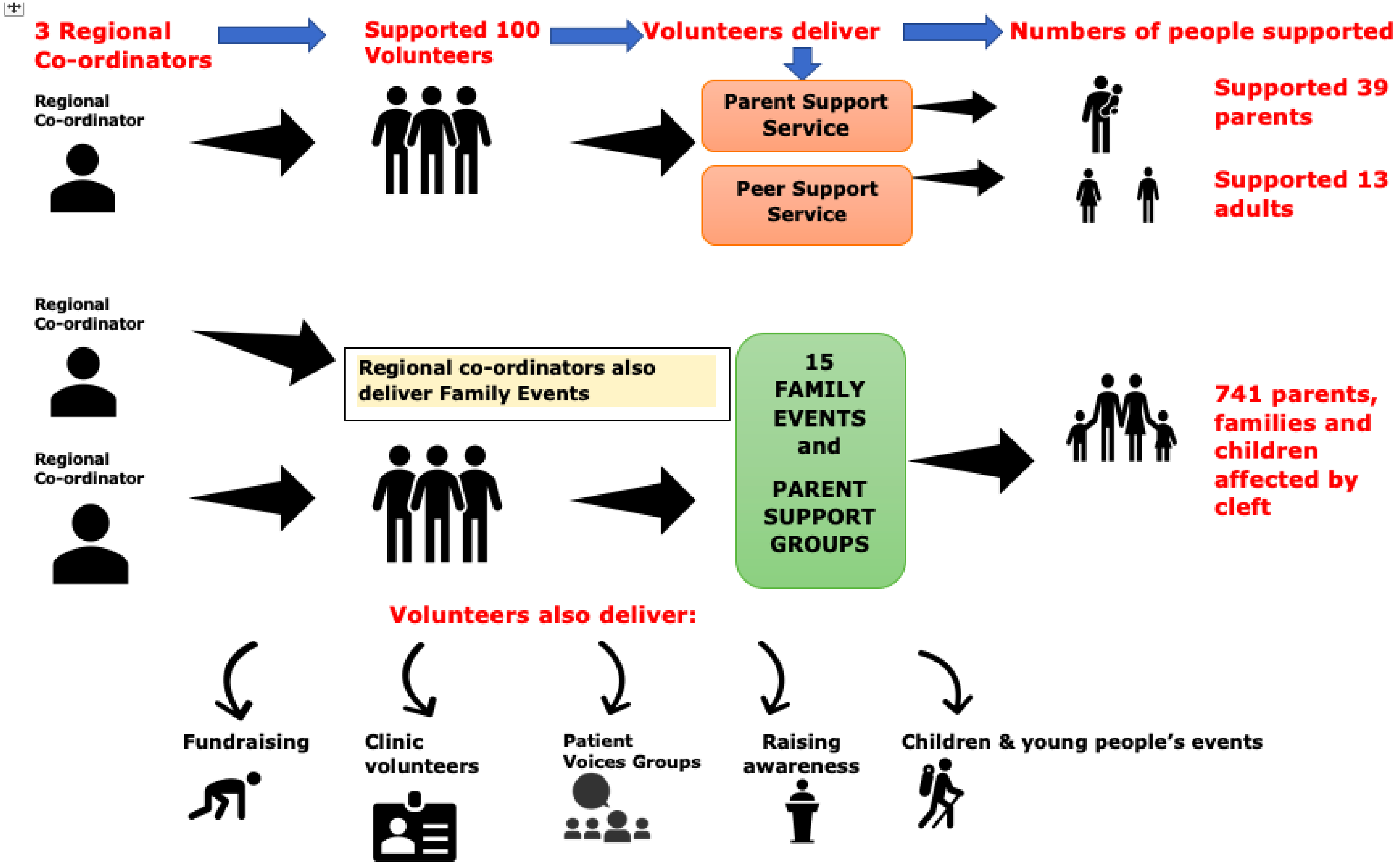
Parent and Peer Support Service: Trained volunteers provide support via telephone or email to parents and to adults born with cleft. The service is managed by the Regional Coordinators: RCs receive the requests for support and match the applicant with a volunteer who has experience of similar issues to provide peer support. CLAPA has recently achieved the APS standard for its Peer and Parent Support Services.

The infographic on page 13 demonstrates how the RC Project delivers services for parents and families of children affected by cleft.

Based on data for year 3 of the project, the infographic shows that three RCs have supported 100 volunteers in 2019/20. These volunteers have delivered 15 family focused events and parent support groups which have engaged 741 people: parents, children with a cleft, and family members of children affected by cleft.

Volunteers have also directly supported 39 parents through the Parent Support Service and 13 adults born with a cleft through the Peer Support Service.

Activity and outputs in Year 3 for parents and families affected by cleft, and adults born with cleft



3 Regional Co-ordinators

Supported 100 Volunteers

Volunteers deliver

Numbers of people supported

Regional Co-ordinator

Parent Support Service

Peer Support Service

Supported 39 parents

Supported 13 adults

Regional Co-ordinator

Regional co-ordinators also deliver Family Events

Regional Co-ordinator

15 FAMILY EVENTS and PARENT SUPPORT GROUPS

741 parents, families and children affected by cleft

Volunteers also deliver:

- Fundraising
- Clinic volunteers
- Patient Voices Groups
- Raising awareness
- Children & young people's events

The diagram also shows that volunteers (supported by RCs) are also involved in a range of other activities aimed at supporting families affected by cleft:

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

Patient Voices Groups

RCs support volunteers in Patient Voices Groups. These groups, designed to meet the NHS service specification for patient involvement, give a voice to people affected by cleft in the development of services for cleft patients.

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 and families' experiences of cleft with medical staff.

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 a cleft. Often these volunteers are young adults born with a cleft, who support the practical delivery of the events and also act as role models to the children and young people.

Activities for children and young people

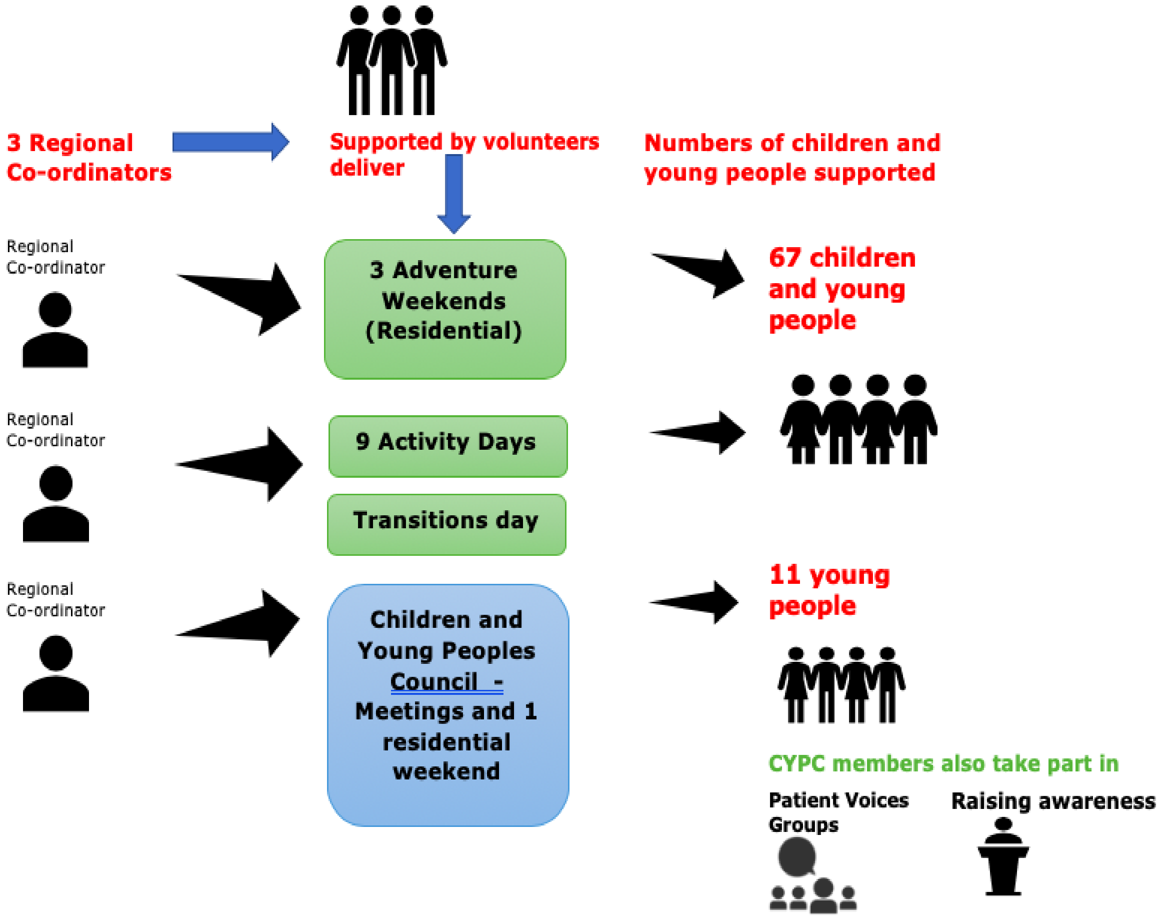
The RC project also delivers activities for children and young people. The RCs organise adventure days and residential weekends for children and young people aged 8-18. The events provide opportunities for children and young people to meet others with a cleft, (reducing their feelings of isolation and providing opportunities for peer-support) but also gives them opportunities to participate in adventure activities, which help to build their confidence and self-esteem.

CLAPA has also developed a Children and Young People's Council (CYPC) - a forum for children and young people to get involved in planning and developing services for young people. The CYPC is involved in developing CLAPA services for young people but has also developed information resources aimed at supporting other children born with a cleft.

The children and young people's events are delivered by the RCs, often supported by volunteers who are young adults born with a cleft.

The infographic on page 15 summarises the activities delivered by the RC project in Year 3 (2019/2020) and the number of children and young people who have engaged in the activities.

Activities and outputs in Year 3 for children and young people



3 Regional Co-ordinators

Supported by volunteers deliver

Numbers of children and young people supported

Regional Co-ordinator

3 Adventure Weekends (Residential)

67 children and young people

Regional Co-ordinator

9 Activity Days

Transitions day

Regional Co-ordinator

Children and Young Peoples Council - Meetings and 1 residential weekend

11 young people

CYPC members also take part in

Patient Voices Groups

Raising awareness

3. Children and young people born with a cleft

This chapter summarises the activities which have been delivered for children and young people over the life of the project, the number engaged through these activities and the outcomes. The project target was to engage 351 children and young people over the life of the project. The expected outcome is:

> **Children and young people affected by cleft lip and/or palate are more able to cope with the challenges associated with living with cleft**

Activities and outputs

Adventure days and residential weekends

The RCs have delivered a series of adventure days and residential weekend events aimed at children and young people 8 – 18 years of age. These events bring children and young people together around an activity (usually an outdoor adventure activity) and provide opportunities for children with a cleft to build their confidence in a non-judgemental environment, but also to meet other children with a cleft and to develop peer-relationships.

Funding to deliver children's events was not included in the original project application, but CLAPA has been successful in raising additional funding from Children in Need, Sussex Freemasons and to deliver these events which are free at the point of delivery.

Table 1 shows that the RCs increased the number of events delivered each year, increasing the number of opportunities for children and young people each year.

Children and Young People's Council (CYPC)

(Children and Young people aged 10-18)
CLAPA has also created opportunities to involve children and young people in the CYPC. Each year, a group of children and young people come together for three meetings and an annual residential weekend to plan and develop new services for other young people affected by cleft

Table 1: Number of activities delivered for children and young people

	YEAR 1	YEAR 2	YEAR 3
Children and Young people	4 Activity days	5 Activity Days	9 Activity days (and 1 transitions day) *
	1 residential weekend	3 residential adventure weekends	3 residential adventure weekends
CYPC	3 Meetings	3 Meetings	2 meetings
	1 adventure weekend residential	1 adventure weekend residential	1 adventure weekend residential

*In Year 3, the RC Project also delivered a transitions day for children and young people in conjunction with the West Midlands Cleft Team

How many children and young people have been reached?

The original target (as agreed in the approved BLF application) was to reach 117 children and young people in each year of the project.

Table 2 shows the number of attendances at targeted children and young peoples' activities in each year of the project.

Table 2: Number of attendances at events in each year of the project

	YEAR 1	YEAR 2	YEAR 3
Target	117	117	117
Total number attending events	95	122	118

The data suggests that the RC project has achieved its target for reaching children and young people in each year except the first year of the project.

However, tracking data shows that many young people attended more than one event, so the number of unique individuals who participated is less than the number of attendances. (Table 3).

Table 3: Number of children and young people attending events

	YEAR 1	YEAR 2	YEAR 3
Numbers attending events	95	122	118
Number of unique individuals attending events in the year	62	67	78

As some children and young people have also attended events over more than one year of the project, the number of unique individuals who have been engaged over the three years of the RC project is 139.

While the RC Project has engaged fewer children and young people than anticipated, (the target was to engage 351 over 3 years) the data shows that the project has achieved a deeper level of engagement with a smaller number of children and young people.

- 71 of the 139 children and young people (over half) have attended two or more events
- 47 (one third) of all children and young people have attended three or more events

The RC Project was successful in creating an increased number of opportunities in Year 3 to ensure that the project could provide ‘repeat’ opportunities for children and young people as well as creating space to engage ‘new’ children and young people in Year 3.

Children and Young People’s Council (CYPC)

Table 4 shows the numbers of young people who have participated in the CYPC in each year of the project.

Table 4: Number of children and young people participating in the CYPC

	YEAR 1	YEAR 2	YEAR 3
Numbers participating in CYPC	13	17	11

Over the three years of the project**, a total of 19** children and young people have been involved in the CYPC – some for one or two years, but some have sustained their involvement for the three years of the Project.

Other engagement with children and young people.
The data above relates to the number of children and young people who engage in dedicated 'children and young people's only' events. However, the project has also reached numerous other children through family days, Christmas events etc. Table 5 shows the additional number of children that the RC Project engaged through family days and events.

Table 5: Number of children engaged through Family focused events

	YEAR 1	YEAR 2	YEAR 3
Numbers of children with cleft attending family events	Not collected in year 1	252	147

Outcomes for children and young people

The purpose of the project (the anticipated outcome) in relation to children and young people is:
Children and young people affected by cleft lip and/or palate are more able to cope with the challenges associated with living with cleft

There are three indicators which demonstrate movement towards the outcome. (These are the indicators as revised after year 1)

Indicator 1:	Children and young people have increased confidence
Indicator 2:	Children and young people feel less isolated
Indicator 3:	Children and young people feel more positive about themselves (positive self-identity)

The RC Project has collected evaluation data from children and young people who attended adventure days and residential weekends.

Data from evaluation carried out in Year 3 (2019/20) demonstrates that the RC Project has been successful in supporting children and young people to achieve this outcome:

- 80% of children and young people reported that they felt more confident as a result of participating
- 89% reported that they felt less isolated
- 90% reported that they felt more positive about themselves.

A comparison with the results from Year 2, demonstrate a similar pattern of achievement and therefore demonstrates the success of the RC Project in delivering outcomes for children and young people. Although in Year 2 a slightly lower percentage of participants reported increased confidence, around 90% of participants in both years reported feeling less isolated and feeling more positive about themselves.

Table 6: Comparison of achievement of indicators over year 2 and 3

Indicators	Year 1	Year 2	Year 3
Children and young people have increased confidence	*N/A	70%	80%
Children and young people feel less isolated	*N/A	91%	89%
Children and young people feel more positive about themselves (positive self-identity)	*N/A	92%	90%

***Outcomes and indicators were reviewed at the end of year 1, so no comparable data is available for year 1.**

To better understand the impact on children and young people, we asked them to provide examples to demonstrate the achievement of these indicators

Confidence
Many of the children commented that they had increased social confidence:
"more confident about meeting new people and making friends", "meeting new people'" "making new friends" "Speaking in front of people"

Many commented on being more confident about their cleft and reported that they were more able talk about their cleft.

> *"Telling other people about my cleft",*
>
> *"talking to people who don't know about cleft"*.

Other young people also reported that they felt more confident about their physical appearance after meeting other children with similar conditions "*I feel more confident about my lip", "my braces"*) but also that they felt more positive and confident in relation to some of the practical challenges in their lives (surgery and dental treatment)

> *"I feel more confident about my operations and getting my teeth out"*
>
> *"More positive about surgery and braces"*

Reduced isolation
As previously reported, the most frequent feedback from children is that attending events makes them realise that they are not 'the only one with cleft'. Children and young people report that 'making friends' with other children with cleft and 'speaking to other people who know what it's like' makes them feel more positive about themselves.

> *"I feel better knowing I'm not the only one with cleft"*
>
> *"You start to understand that there are other people with the same as you and it supports you" Boy, 14*
>
> *"Knowing that there are other people that look like me" Boy, 11*
>
> *"Making friends who are the same as me – helping them and them helping me" Boy, 11*

Positive self-identity /feeling more positive about themselves
Around 90% of children and young people said they felt more positive about themselves as a result of participating. We asked children and young people in what way they felt 'more positive about themselves'. Responses included:

> *"My appearance"*
>
> *"The way I speak"*
>
> *"I feel more positive about being myself"*
>
> *"My cleft and myself!"*
>
> *"More positive about my cleft and more confident to talk about it"*

The number of children who have attended multiple events suggest that children and young people recognise and value the impact of their participation. The evaluation data also suggests that children benefited from the more intense level of engagement, with children who had attended more than one event able to identify how the impact of their involvement carried over into other aspects of their lives.

> *"It boots up my confidence every time I come" Boy, 11.*
>
> *"I get more confidence and new friends whenever I do something with CLAPA' Girl, 11*

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 her confidence and sustaining a more positive self-image.

X is an 9-year-old girl. She attended her first children's Adventure day in 2018, when she was 8 years old (the minimum age to attend Adventure Days).

X's mother said The Adventure Day came just at the right time for X as she "had been feeling quite self-conscious about her cleft." After the event, her mother reported "meeting the other children today made her feel much more positive."

X enjoyed the first Adventure Day and was excited to go to second children's event in January 2019. Having attended two 'day events' X felt confident enough to go a residential weekend with CLAPA in Spring 2019.

X said the best thing about the residential was '*making new friends and having people to talk to who understand about having a cleft* '. She says that hearing about other people's experiences made her more positive about her cleft and finding out about other children's experiences of surgeries made her more confident about her own forthcoming operations.

X attended has attended two more events in 2019. Her mum says that each event helps to build X's confidence.

Her mum wrote: "We really appreciate the time and effort that goes into organising these events and we're always thrilled when X returns that little bit more confident"

X’s mum also highlights how important it was to her daughter to get the opportunity to reconnect with her CLAPA peer group to consolidate her sense of positive self-identity. She described how her daughter had been very sad and upset after an unkind comment about her appearance, but that the fact that she knew she had a CLAPA day coming up had helped her ‘get through it’.

“Knowing X was going to spend a whole day with other children with clefts, just two days after this horrible comment had a really positive effect on X and us. We are so grateful that you organise these events and take such great care of X when she's with you. It has all boosted her confidence enormously and she looks forward excitedly to the next one.

“These events have made such a difference to X and the timing has often been perfect – they help to rebuild her after she’s experienced an unkind comment or lack of confidence.”

What’s important to children and young people?
We also asked children to tell us in their own words why they come to CLAPA events and the most important thing that they got from events.

The statements highlight the extent to which children and young people with visible differences feel isolated and the impact on their emotional wellbeing of meeting other young people who have shared experiences of cleft.

> *“Just knowing I’m not the only one with cleft”*
>
> *“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”*
>
> *“CLAPA has made me braver. I was so nervous before as I had never met anyone else [like me]. It has made a real change in my life and how I look at myself. [...] I used to think I was weird and ugly, whereas now I can look at myself and say I like what I see! “*
>
> *“It makes me feel happy to meet people like me”*
>
> *“No-one stares at me because they have cleft too”*
>
> “*Having fun without having to worry about my appearance*”

Parents assessment of impact on children.
We also asked parents to assess the impact on their children of their participation in CLAPA events. Table 6 shows how parents rated the impact on their children (against the same indicators) and compares that with self-reported scores given by the children themselves. It is interesting to note that parents reported higher scores for achievement of every indicator.

Table 7: Comparing parents and children's assessment of impact

Indicators	*Percentage of **parents** who report positive change in their child	% of children and young people reporting positive change
Children and young people have increased confidence	91%	80%
Children and young people feel less isolated	96%	89%
Children and young people feel more positive about themselves (positive self-identity)	100%	90%

*% of parents who responded, 'to a great extent 'or 'to some extent'.

We also asked parents/carers to provide examples of impact to substantiate their scores.

Comments from parents reflect the challenges for their children of being 'the only one with cleft' and demonstrate how meeting other children and young peoples with cleft has helped their child to cope with the challenges of living with cleft.

> *"Not feeling like the only person in the world with a cleft has helped my daughter to feel better able to deal with having a cleft"*
>
> *"Hearing other cleft children talk and realising their voices are similar and not "wrong". Realising it is not a big deal having a cleft"*
>
> *"Talking with CLAPA friends about operations, and things like starting secondary school has been so helpful for her."*
>
> *"After finding out my daughter needed dental surgery as a direct result of having a cleft, she was extremely upset. Knowing a CLAPA residential was coming up in a few weeks made a world of difference as it gave her something cleft-related that was positive to focus on."*

Parents provided also specific examples which demonstrate that their children felt more confident and positive about themselves

> *"He is willing to discuss it [his cleft] with his class in order to raise funds for CLAPA"*
>
> *"He talks about it in school, and provides support to a friend in school who has a cleft"*
>
> *"She talks about herself with more confidence and talks about her 'cleft friends' to her non cleft friends with great confidence."*

Additionally, 91% of parents said that participation in CLAPA **helped their child to deal positively with cleft**. Parents provided examples that demonstrated that their children were better able to deal with cleft related issues, but also that their increased confidence and positive self-image was evident in other aspects of their life.

> *"X has increased massively in confidence and it has carried through into school hours and home"*

> *"He has gained so much confidence in himself and was able to assist a younger child at school explain about their cleft to their class."*
>
> *"Her confidence in school has grown loads over the years since coming to CLAPA events"*

One parent also highlighted the impact on the whole family

> *"It helps our whole family to have a happy child, who suffered a lot from bullying."*

Feedback from other stakeholders

We also gathered feedback from NHS Cleft Teams on the value of the activities for children and young people.

Cleft Teams stressed the psychological impact on many children living with a cleft and in particular the impact of isolation. Cleft Teams reported that the value of CLAPA activities was in providing children and young people with a *'sense of community and connection'* and the critical importance to children of knowing they were not the only person with cleft.

Cleft Teams also highlighted the value and importance of CLAPA services in complementing the medical services which they provided.

> *"As professionals, [without CLAPA] there would be no places to direct isolated and struggling young people feeling affected by the impact of being born with a* cleft.

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 in developing CLAPAs youth services and more broadly in giving a voice to young people to influence the development of cleft services.

In each year, CLAPA delivered a residential team building event for the CYPC (as the membership revolves each year) and facilitated three meetings where they took part in workshops and activities to further the 'business 'of the CYPC.

Over the life of the project, the members of the CYPC 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'
- developed a comic book and other resources aimed at informing children and young people about cleft and about cleft services,
- responding to research proposals about children/young peoples' experience of cleft services,

Members of the CYPC have also been involved in delivering awareness raising talks to NHS staff or to their own school/community.

There are 12 places each year on the CYPC. Most children and young people participate in the CYPC for more than one year, with some participating over each of the three years of the project. In total, 19 children and young people in total have participated in the CYPC over the life of the project.

Impact of involvement in the CYPC

Most young people reported that their motivation for joining the CYPC had been 'to help other children and young people to get support'.

Children and young people reported that they had learned new skills through their involvement in the CYPC (for example through developing a comic book for children born with cleft) and expressed pride and satisfaction that they had been able to use their own experiences to help other young people.

> "*We've created things to help other people*"
>
> *"I've been able to use my experiences to help other young people"*

Their comments also highlight the impact of their involvement in the CYPC on their own confidence in developing a more positive self-identity. Young people were able to articulate how their involvement in the CYPC had helped them to deal positively with the cleft related issues in their own lives.

> '*The CYPC makes you more confident about yourself'* Boy, 13
>
> *"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. 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."* Girl 16
>
> *'I have met some amazing people and had the chance to share my own story in order to positively impact on other people's lives. I have grown more confident in myself and proud of my cleft'* Girl, 16
>
> *"I feel I have somewhere to go where my cleft doesn't define me, and I can talk to people about cleft issues without having to explain myself. It's also been great to have such great role models to look up to and keep positive. I have grown in confidence through the CYPC and have loved having the chance to improve cleft treatment for others and making sure that CLAPA can reach as many people as possible"* Girl, 15
>
> **"***The CYPC made me feel less alone and more happy with what I look like."*
> *Girl, 16*
>
> *"Confidence, improved self-esteem, friends, encouragement and laughter!"*
> Girl, 17

How does involvement in the CYPC support children and young people to be 'more able to cope with the challenges associated with living with a cleft'?

As the CYPC meets at least 4 times each year, and many young people have participated over more than one year, the CYPC participants are young people who have had a longer -term and a more intensive involvement (than children who attend a one-off event). This has enabled them to develop supportive peer relationships with other young people with cleft.

Young people's comments underline the importance of these peer relationships in building a positive self-identity and in supporting their emotional wellbeing.

Able to be yourself without cleft defining you because everyone has one

Feel like you are with people who understand you

Nice not to feel different, not to be self-conscious all the time

Not feeling alone

Feel equal

Young people also reported that being a member of the CYPC had given them access to practical advice and information from peers - everything from surgery to dealing with bullying at school.

Learning about other people's experiences had supported them to feel more confident in making decisions about their own surgery and given them helpful advice on other issues. They also reported that meeting young people who were older than themselves had given them positive role models which made them feel more confident in themselves and about their cleft.

You are able to talk about surgery and the reality of it. Advice on how to handle it makes you feel so much better/reassured before you go in [for surgery].

it has helped me to meet other people with a cleft that are older and have had the same and more experiences as me

it has helped to me embrace my hearing aids and not feel embarrassed by them

it has helped me to learn about everyone's experiences with treatment and helped me to decide my next steps with surgery

I'm more confident about the way I look and about going to hospital appointments.

Case studies

The following case studies highlight the impact on young people of being involved in the CYPC.

16-year-old girl involved in the Children and Young People's Council for over 3 years.

Prior to her involvement in CLAPA, X didn't know anyone else with a cleft, and her comments describe the impact of her cleft on her self-esteem. Her involvement in the CYPC has given her friendships, has built her self-esteem and sense of identity, and also built her confidence. She is now confident enough to share her experience of living with cleft to help other young people.

“Before I was involved in the CYPC I felt like I was a disappointment to life as I thought I was the only one with a cleft. When I found out I was not the only one with cleft I felt a lot happier.

I feel like the most important part of being part of the CYPC is being with my great, amazing and funny friends. I also feel like I have gotten a great amount of positivity out of this group. This group is simply amazing and so are the people.

X also feels that she has learned coping mechanisms to deal with cleft – she reports “I have learned how to deal with having a cleft by listening to the ways that others deal with a cleft’

“I am now a lot more confident in my speech and making decisions for myself.’

X’s mother also commented on the impact of involvement in the CYPC on her daughter

“……discussing issues with other teenagers that are in the same position as herself and being able to relate to them have been so important to building her confidence and self-esteem - her confidence has improved dramatically”.

X is keen to use her confidence and her own experience of dealing with cleft to help other young people born with cleft.

“I enjoy sharing my experiences with my CLAPA friends as I know it will help someone. I also enjoy giving feedback to hospitals and I enjoy impacting on other people's lives.”

Through the CYPC, she has been involved developing resources for young people to help them to understand more about hospital procedures and has provided feedback to Hospital Trusts on their information for children and young people.

She also participated in training in peer mentoring (delivered by CLAPA) and says that as a result, she has *‘developed self-confidence to share my experiences to help build another person’s confidence……. knowing that I made an impact on their life.”*

15-year-old boy who has been involved in the CYPC for over 3 years.
He describes the impact of his involvement on his confidence and his self-esteem. His mother describes the impact of his improved confidence on his life and on the whole family.

X says that he joined the CYPC ‘*to meet other young people with cleft’* has enjoyed making friends with other young people and finding out about other people’s experiences of living with cleft. He says that getting to know other young people with cleft has *‘made me more confident and I feel more positive about myself’.*

He is proud of the achievements of the CYPC, especially the comic book and welcome pack that have been developed to help other young people with cleft.

X says that his biggest personal achievement resulting from his involvement with the CYPC been his growth in confidence.

"My biggest achievement is my confidence**"**

Being a member of the CYPC has 'helped my confidence drastically and I'm able to talk in front of people.'

X's mother has also seen a massive increase in his confidence as a result of his involvement.

I think X's confidence is the most important thing he has gained from the CYPC - meeting people in a similar situation has been very important in helping X realise he is not alone with his cleft. It is good to know that there are others who can relate to X and he loves the fact he has friends from all over the country.

X is now coaching his younger brother's rugby team. This is something he would not have done before - I think his increased confidence is in part due to the CYPC.

X's mother concludes:

'X's involvement in CYPC has benefited both him and the family massively.'

Children engaged in family day and family events

While the primary activities for children and young people are the activity days/residentials and the CYPC, the RC Project also reaches hundreds of younger children through family days and family events.

Table 8: Number of children attending family focused events

	Year 1	Year 2	Year 3
Number of children attending family focused events	Not collected	252	147

Although the focus of these events is to provide opportunities for parents to develop peer support networks, parents comment that their children also benefit from attending. Comments include:

> *'It helped my daughter to feel that she is not on her own'*
>
> *'Knowing he is not the only child with a cleft.'*
>
> *'It's amazing - When my son got his hearing aids, it made such a difference to see other children with them.'*
>
> *'My child gets a feeling of belonging and being understood. That there are positives to being born with a cleft.'*
>
> *Attending CLAPA events helps my daughter understand that she is not the only one, nor is she abnormal.*

In a survey of parents who had attended family events in 2019/20, around two-thirds of parents reported that involvement in CLAPA family events had had an impact on their children:

- 68% felt that attendance at family events increased confidence of their children
- 64% reported that it helped their children to feel less isolated
- 66% reported that it helped children to feel more positive about themselves

Overall, 69% reported that participation in family events had increased their child's capacity to deal positively with cleft.

It is interesting to note that of those parents who reported little or no impact on their children (approximately one-third of parents), all but one were parents of babies or very young children who acknowledged that their child was still too young to benefit from the involvement in events.

4. Adults born with a cleft

This chapter summarises the activities and outcomes for adults born with a cleft. The project target was to reach 45 adults with a cleft. The project outcome for adults is:
Adults affected by cleft lip and/or palate are more able to cope with the challenges associated with living with cleft

Activities and outputs

Peer Support service

The key service aimed at supporting adults with cleft is the Peer Support service which is a telephone and email support service delivered by volunteers.

Adults born with a cleft who contact the peer support services are matched with a trained volunteer (another adult with cleft) who can offer informal support and advice and signpost to other services.

Over the three years of the RC Project has matched at total of 47 adults with a peer supporter. The target (as per the project application) was to reach 45 adults with a cleft.

Table 9: Number of adults receiving peer support each year

	Year 1	Year 2	Year 3
Number of adults receiving peer support	6	28	13

Adults sought help and support around a range of issues including surgery, feelings of isolation, concerns with speech, appearance, delayed diagnosis, decisions around becoming a parent and requests for information about psychological support.

Other engagement with adults with cleft

In year 2 of the RC Project, (2018/19) CLAPA received funding to develop new services for adults born with a cleft. As part of the development of this service, the Regional Coordinators organised events in their areas to engage with adults. As a result, the RCs have engaged or re-engaged 30 adults born with a cleft in that year through the events.

Outcomes for adults

Adults supported through Peer Support Service

CLAPA has less direct evidence of impact on adults as the number of adults engaged in the peer support services is small and there have been challenges in getting evaluation feedback from users of this service.

However, those who have provided feedback highlight the quality of the service and the value of peer support.

> *'I was amazed with how quickly a response I got after initially contacting the CLAPA team. My experience with the support was summarised as efficient, friendly and supportive. I am very grateful'*
>
> *'S [peer supporter] was amazing. He literally called me to chat for about an hour one time and I was so comfortable with him. We discussed various issues and more than what I initially contacted for. I can't say I am fully ok. But I definitely have a more positive outlook on my life going forward thanks to S.'*
>
> *'made me feel at ease and made me realise my feelings were normal!'*

Adults engaged through the roadshows/events in Year 2

In evaluations from those adults (30) who engaged with CLAPA as a result of the Roadshows and events in Year 2 identified that:

- just under 90% reported that they had increased confidence as a result of engaging with CLAPA
- 95% reported that they felt less isolated
- 95% reported that they felt more positive about themselves

Feedback from participants on what they got out of attending the events highlighted the extent to which many adults born with cleft felt isolated and had lacked any form of peer support. Comments included:

> *"Hearing others experience and knowing I'm not alone"*
>
> *"Realising some things don't only happen to me – others have had the same conditions and problems that I have had which is reassuring"*
>
> *"Feeling supported and accepted."*

5. Parents and families

This chapter summarises the activities, outputs and outcomes for parents and families of children born with a cleft. The project target was to engage 291 parents/families over the life of the project.

Activities and outputs

The RC Project delivers a range of events and services for parents and families through its volunteers.

Family-focused groups and events

Family events provide opportunities for parents and families to meet other families affected by cleft in an informal setting and develop supportive peer relationships. Events include:

- family fun days to bring together families with children affected by cleft
- support groups for new parents of children born with a cleft (in the past these type of groups were known as Happy Faces Groups)
- fundraising events etc.

While most family-focused events and group are delivered by volunteers, RCs have also delivered family days in areas where there are fewer volunteers.

Over each of the 3 years of the project, the RC Project has supported 15 family focused events each year, engaging hundreds of parents, siblings and other family members (grandparents etc).

Table 10: Numbers of parents and family members reached by the RC Project

	Year 1	Year 2	Year 3
Number of Family events delivered	15	15	15
Number of people attending (parents, siblings and other family) *	Approximately 800	870	741

*These numbers will contain some double counting as some families have attended more than one event. Also, the numbers should not be aggregated over the three years as many families will have attended events in all three years of the project.

The number of parents and families engaged through family days and events consistently exceeds the project targets. The original target (as included in the project application) was to reach 97 parents and carers each year. Although the number of parents /families exceeds this target, it is important to recognise that the level of engagement of parents/families is very variable. Some parents and families attend one event a year, while others participate in support groups which meet more regularly, and some receive one-to-one support through the Parent Support service.

Over the life of the RC Project, there has also been a significant increase in the use of social media which has increased the reach of the RC Project. RCs have set up local Facebook groups which have proven to be a successful mechanism for families to 'stay connected' between events. These groups are not only social networks, but also operate as virtual support networks – parents frequently post requests for information and advice to the groups.

> *'Being involved in the Facebook group gives me easy access to information and experiences from other parents whose children are further along their cleft journey.'* (Parent comment via on-line survey)

Parent Support Service
This is a service delivered by volunteers. People seeking support make contact with the service through the CLAPA website. RCs match the person seeking support with a trained volunteer - usually someone with previous experience of the issue or condition.

In 2018/19, CLAPA received Approved Provider standard for its Parent and Peer Support Service.

Table 11 shows the number of parents who have been matched with a trained volunteer through the parent support service over the life of the RC Project

Table 11: Number of parents supported through Parent Support Service

	Year 1	Year 2	Year 3
Number of parents supported	31	49	39

The RC Project has collected feedback from people who have been supported through the Parent Support Service. It highlights the value of peer support to parents and the and the impact on their capacity to cope with cleft related issues.

> *'[parent supporter] is great. She (along with the support on the FB group) has been amazing. I feel much stronger and positive now than I did after my 20-week scan. Thank you.'*
>
> *'I found speaking to [parent supporter] extremely helpful. She was there for me from the moment I first contacted CLAPA, up until recently when my daughter had her surgery. Plus, she has said she will continue to be there for me in the future. She has been invaluable to me and my partner throughout our cleft journey.'*
>
> *'Thank you so much for setting me up with. [parent supporter]. We have been in touch and she has reassured me greatly by letting me know what her son has been through and how well he is doing. I am aware that no two children are alike, but it helped me realise life can become regular again.'*

Outcomes for parents and families

The project outcome in relation to parents and families is:

Families affected by cleft feel better able to support their child

There are three indicators:

Indicator 1:	Parents/carers have increased confidence in supporting their child with issues related to cleft
Indicator 2:	Parents/carers have access to a local support network
Indicator 3:	Parents/carers feel better able to cope with the challenges associated with cleft

In a survey of parents who participated CLAPA services in year 3 (2019/20):

- 94% of parents report having increased confidence in supporting their child with issues related to cleft
- 91% report that they have access to a local support network
- 94% report feeling better able to cope with the challenges associated with cleft

(Results show aggregated percentages of parents who agreed 'to a great extent' and 'to some extent.')

It is important to note that parents and families have different levels of engagement with the Project:

- the Parent Support Service provides one-to-one support from a volunteer
- Family days and events provide a relatively light touch involvement (one or two events per year in some areas), but many families attend over several years and maintain contact with other families between events.
- On-line networks are very 'light touch', but the Facebook groups have increasingly become a mechanism to keep people connected between meetings and many parents actively use the Facebook groups for information, advice and support from the cleft community.

While many parents have been involved in CLAPA over a number of years and have attended various events (and we would anticipate that these individuals would have benefited the most from their involvement through the development of peer-relationships), it is interesting to note that over 90% of all parents surveyed felt that their involvement in CLAPA had impacted positively across each of the three indicators. Nearly one fifth of the parents who completed the survey had been involved for less than a year.

A parent who had attended her first ever Family event commented on how it had helped them:

> *"We have already met a couple who gave a lot of advice for the next challenges with procedures we face. I think it will be of great benefit in the future to speak with parents who have gone through what we will go through."*

The survey responses from parents in Year 3 are consistent with the results in year 1 and 2, which consistently show over 90% of parents reporting positively against each outcome indicator. (See Table 12). These results demonstrate the success of the RC Project in achieving the key outcomes for parents and families.

(Note that indicators for this outcome have remained the same over the life of the project, so we can provide data over all three years of the project.)

Table 12: Percentage of parents achieving outcome in each of three years of the project

Indicators	% achieving indicator in year 1	% achieving indicator in year 2	% achieving indicator in year 3
Parents/carers have increased confidence in supporting their child with issues related to cleft	94%	95%	94%
Parents/carers have access to a local support network	97%	96%	91%
Parents/carers feel better able to cope with the challenges associated with cleft	94%	92%	94%

Parents also provide written feedback and examples to demonstrate the achievement of the indicators:

Indicator 1: Parents/carers have increased confidence in supporting their child with issues related to cleft

> *'It has helped me to be more educated about clefts and feel more prepared for my child's journey through his operations - it has a positive impact on our whole family.'*
>
> *'CLAPA is everything to us as a family. The events are vital in boosting confidence and not feeing alone. Life would be harder and much more lonely without the wonderful events and contact with CLAPA and other families.'*

Indicator 2: Parents/carers have access to a local support network

> *'CLAPA allows me to meet others affected by the same condition which makes me feel less alone. Also, benefits me greatly to speak with others and share experiences.'*
>
> *'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 in understanding his identity and feeling normal.'*
>
> *'It makes us feel less isolated with the issues we face as others understand what we are talking about.'*

Indicator 3: Parents/carers feel better able to cope with the challenges associated with cleft

> *'Hearing from other parents about strategies to talk to your child about cleft in a positive way to build their confidence and resilience has been very helpful. Also, strategies to pass to my child to support them to talk to others about it have helped.'*
>
> *'The support and guidance from others has been invaluable. CLAPA has given us a community where it's normal to talk about cleft - where it's not a huge deal and where people gasp.'*

The following statements from a parent sum up the personal impact of involvement in CLAPA and also demonstrates how this how this involvement helps whole families to feel better able to support their child.

'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 residentials 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!'

'My daughter has benefitted from meeting other children with a cleft that "mirrors" her own. I think it has helped her process her own self-image as she gets older. Through attending the summer and Christmas get togethers (and more recently adventure days) my daughter has started to make friends with other children affected by clefts.

We as the parents have made friends with other parents of children born with a cleft and we're going to continue to meet outside of CLAPA events. I don't see how we would have built those relationships without CLAPA giving us the opportunity through the many events they organise and making it so easy!

My daughter is of an age now where she studies herself in the mirror quite a bit, so seeing others in person must be helping her understand there are many others like her, some on their way to becoming goods friends!

It has also benefitted our other children born without a cleft to see other children like their sister who were born with a cleft.'

6. Other outcomes and impact of the RC Project

The original project application identified two key outcomes for the RC Project. However, the project has also delivered outcomes for volunteers, and has had a wider impact on influencing services for people affected by cleft.

Outcomes for volunteers

As previously stated, volunteers are central to the delivery of events and activities through the RC Project, and a key role of the RC is to recruit, train and support volunteers.

The RCs have recruited and trained 45 new volunteers over the life of the project and supported and supervised around 100 volunteers each year.

Table 13: Number of volunteers involved each year

	YEAR 1	YEAR 2	YEAR 3
Number of active volunteers at start of year	95	89	86
New volunteers recruited in the year	14	23	14

Evaluation data from Volunteer Training Events in 2019/20 suggest that Regional Coordinators have been successful in delivering high quality and relevant training.

- 90% said that the Development Days were 'very effective' or 'extremely effective' in supporting them in their role as a volunteer.

- 80% said they learned new information and gained skills which would help in their volunteering role 'to a great extent'.
    - 20% said 'to some extent'

The RCs have also been successful in supporting and managing volunteers**.**

- 100% of volunteers said they felt valued as a volunteer

The evaluation also highlighted that many volunteers developed skills and experience which were valuable in other areas of their life.

- 85% said that they had gained skills and experience through volunteering which were useful in other areas of their life.

  'Improves my communication skills and encouraged me to strive for *personal goals in career within a caring role at a hospice. Knowing that helping and supporting is a great asset I never knew I had before'*

  *'Communication skills, being able to support others, networking skills***'**

- 95% said that they had gained confidence as a result of their volunteering involvement

Many of CLAPAs volunteers are parents of children with a cleft. Many reported that their motivation for volunteering was that they had received support from CLAPA in the past and wanted to 'give back' to help other parents in similar circumstances. These volunteers record high levels of personal satisfaction with their volunteering role.

> *'Satisfaction of knowing what I do helps others'*

> *'I enjoy helping people who are in the same situation I was.'*

However, feedback also shows that their involvement as volunteers has also built their own capacity to deal with cleft related issues.

The following statement was written by a mother of two-year-old child born with cleft. The mother volunteers as a member of a Patient Voices Group.

> *'As a member of a Patient Voices group I have met other parents and young people affected by cleft and learnt from their positive attitudes about how to approach cleft related issues on my journey with my daughter. I've also learned about interesting research projects undertaken by professionals that are informative and often surprising, challenging my assumptions on what is known/unknown about cleft conditions and associated treatments.*
> *This will give me increased confidence to question health practitioners about my daughter's treatments in the future.'*

Adults with a cleft involved as volunteers
Many of CLAPAs volunteers are adults born with a cleft. In Year 3, 21 of the 100 volunteers were adults with a cleft.

Again, while many adults born with a cleft reported that they had volunteered to 'give back' to the cleft community, they also reported on the impact of volunteering on their own confidence and self-esteem

> *'It's made me more confident when I speak to groups of people'*

> *'It makes me feel good about myself, knowing that I am making a positive difference in people's lives.'*

One young adult volunteer (with a cleft) who supports children and young people's events reported on the impact that volunteering has had not only on his self-esteem but also on his own capacity to deal with cleft related issues in his life.

> *'I never thought that by volunteering with CLAPA it would make a difference in my own life. Before I joined CLAPA [as a volunteer] I'd 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 are also no words to explain the good feeling you get inside when you read the good feedback left by the children after a residential trip. 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*.'

Another adult born with a cleft who volunteers on a Patient Voices Group reports that volunteering on the group has been significant not only because the Group has been able to influence services for people with a cleft, but also because of the impact on herself and her capacity to deal with her cleft in everyday life.

> *'This group helps me understand and accept myself more and I was able to speak about my condition without feeling embarrassed or being judged. This has helped me being more open about cleft lip in my everyday life as well.***'**

Influencing services for families affected by a cleft

The RC Project has been active in supporting people affected by cleft to engage in Patient Involvement Groups which aim to give a voice to patients in the design and delivery of healthcare services. However, the development of Patient Involvement structures is not consistent across the three regions, and even where there are well developed Patient Involvement structures, these have not always worked effectively due to lack of staff time/resources in Cleft Teams to attend these forums.

Volunteers have voiced frustration that relevant staff from Cleft Teams cannot always attend the Patient Involvement Groups which jeopardises the effectiveness of these forums. However, volunteers could identify a number of examples where they had been successful in influencing the development of new services or resources.

The RC Project has played a critical role in facilitating volunteer input to the Patient Involvement Groups.

> *'Our patient involvement group is currently on hold due to staff/ structure changes within our team. We would really struggle to envisage running the group again without CLAPA's support.'*
> Cleft Team member
>
> *'We value CLAPA highly in our team. Not having the resources would be hugely detrimental [to the patient involvement group].'*
> Cleft Team member

Outside the formal structures, the RCs have also been proactive in seeking other opportunities to raise awareness of the needs of cleft patients through delivery of awareness raising talks to other non-specialist medical professionals. These have included the delivery of volunteer led 'awareness raising' input for:

- GP practices
- two cohorts of trainee midwives at the University of Birmingham.
- A young person from the CYPC has also spoken about her experience of services at a training day for Cleft Teams

One of the key strengths in the CLAPA approach is the involvement of volunteers in any awareness raising/training events. Feedback from the awareness raising session with trainee midwives highlighted the impact of hearing from a person with 'lived experience' of the challenges of living with cleft.

When asked to identify the most useful elements of the session, feedback included:

> *'Personal story - Understanding people's feelings and how they live with cleft'*
>
> *'Meeting a service user and understanding what is required from a midwife from a parent's perspective will help when giving advice and care'*

The feedback from the midwives session also demonstrated that it had been successful in:

- **raising awareness of cleft and of the impact on famili**es

  'Did not realise the impact cleft can have on a person for years into their lives'

> *'I now understand that cleft lip and palate can be associated with hearing problems'*
>
> *'This session highlighted to me the impact this diagnosis can have and the length of the journey (the process and treatment for CLP)'*

- **raising awareness of the services available to support families affected by cleft.**

> *'I'm more aware of what parents may be going through and what services that you can refer families to'*

Trainee midwives could also provide real examples of how they would change their practice based on the learning from the session.

> *'I will provide more emotional support and knowledge and be able to direct parents/families to sources of support'*
>
> *'Will get in touch with local cleft lip and palate team for more info and share with health visiting team'*

And a final comment from the volunteer who delivered the session.

> *'I thought yesterday was great and felt proud that I could pass my experiences on to help midwifes understand how cleft affects the whole family for life.'*

7. Conclusions and learning from the project

Is there a need for the project?

We surveyed Cleft Teams (14 respondents across 5 Cleft Teams) to explore their reasons for referring to CLAPA and to identify the needs which the RC Project met.

Feedback from the Cleft Teams highlighted the sense of isolation which can affect parents/families and children with cleft. They identified that the RC project provided access to a 'community' which enabled children and families to realise that they were 'not the only one' but also provided a peer network which provided practical and emotional support. Comments from the survey demonstrate the Cleft Teams perceptions of the needs that the RC Project is addressing.

> *'Through CLAPA, people get support, friendship and a sense of community – the feeling that they are not the only one'*
>
> *'Support from people that live with cleft on a daily basis (whether they be parents, siblings, grandparents or patients themselves) that we are unable to provide as professionals'*
>
> *'Support, advice, sense of community'*
>
> *'Support / integration with other children / young people with similar conditions'*

Cleft Teams also highlighted the distinctive elements of CLAPA's support and the 'additionality' for people affected by cleft.

> *'CLAPA provides a very different kind of support to the NHS service and it is important that there is something separate for families. A lot of individuals affected by cleft would feel much more isolated if they did not have support through CLAPA and the services they provide.'*
>
> *'Medical teams cannot provide the sense of community and belonging that CLAPA does. It normalises experiences for cleft patients as it connects them as a group and offers them spaces and forum to meet and exchange. This is crucial to their well-being and extensively used by our patients*.'

Has the RC Project addressed the need?

A key strength in the project design is the creation of volunteer led peer networks which provide families affected by cleft with access to a 'community' which provides practical and emotional support.

Access to a community
The project has been successful in giving parents and families access to a community of other families with lived experience of cleft. The most common response to questions about what people get out of being involved in CLAPA is 'knowing that we are not alone'.

Practical and emotional support
Evaluation evidence demonstrates that parents value the opportunity to meet others with whom they can share experience of managing their child's condition and to learn strategies from other parents about supporting their child emotionally.

- Parents report that that they get invaluable support and advice from other parents of children who have already been through surgeries that their children

are still to have. This gives parents confidence and helps to allay their anxieties about their own children's surgeries
- Parents also recognise the importance of their children meeting other children with a cleft and 'knowing that they are not the only one'. They also report that family events are important for siblings of children born with a cleft to help those children understand that there are other children born with a cleft.

At an emotional level, parents find it invaluable to find other parents 'who understand what we are going through'. Evaluation evidence from parents clearly demonstrates that access to a support network has built their confidence and capacity to deal with the challenges they face.

Supporting children and young people

Feedback from children and young people demonstrates the extent to which children with a cleft feel isolated – the most common feedback given by children about what they got out of their involvement in CLAPA was 'knowing I'm not the only one with a cleft'.

Feedback from children and young people (and their parents) demonstrates the impact of their participation.

- Children and young people report that 'making friends' with other children with a cleft and 'speaking to other people who know what it's like' makes them feel less isolated and more confident and positive about themselves.
- Children and young people also report that talking to other people who've already had the surgery/operation that they are about to have, or finding out how other people deal with problems like 'people staring at you' gives them practical strategies and builds their confidence to deal with the challenges of living with a cleft.

Has the project delivered the expected outcomes?

Children and young people

While the project did not reach the targeted number of children and young people, the project provided a more in-depth engagement for a smaller number of children, with over half of the children attending more than one event.

The evaluation feedback from children and their parents demonstrates that the project has reduced isolation, built confidence and a sense of positive self-identity for nearly 90% of children and young people who attended events.

Young people who had benefited from a more intense level of engagement (those who attended multiple events) could also identify how the impact of their involvement carried over into other aspects of their lives.

These findings suggest that any future model of support should provide opportunities for longer-term sustained engagement rather than one-off interventions to maximise the impact for children and young people.

Adults born with cleft

The project provided support for 47 adults born with a cleft (exceeding its target of 45) through the Peer Support Service. Little formal evaluation evidence is available from this service but comments from users demonstrate that support from peers has helped users to cope with challenges associated with cleft.

Parent and families

The RC Project has exceeded its targets for engaging parents and families by a significant margin. The RC Project has engaged nearly 800 family members in networks each year.

While engagement in activities/events can be relatively light touch (for example, attending annual Christmas events) the RC Project has been successful in creating access to a 'community' and the evaluation evidence demonstrates that 90% of parents report that they feel 'better able to support their child' as a result of their involvement in CLAPA.

Other outcomes delivered by the RC Project

- **Raising awareness of cleft and influencing services**

Alongside the direct delivery of activities aimed at supporting children and families, the Project has also been successful in supporting people affected by cleft to raise awareness of the needs of cleft patients and influence services for cleft patients and their families.

- Where formal Patient Involvement structures exist, the CLAPA RC Project is recognised as a key partner in supporting groups of volunteers to engage in these structures. However, lack of NHS staff time and resources have at times undermined the effectiveness of Patient Involvement groups as mechanisms for influencing services.
- RCs have also been proactive in finding other opportunities to engage with non-specialist medical staff to raise awareness of cleft and improve the responses of services providers.

- **Outcomes for volunteers**

The evaluation also highlighted that many volunteers developed skills and experience which were valuable in other areas of their life.

- 85% said that they had gained skills and experience through volunteering which were useful in other areas of their life.

Learning from the project

The level of activity and the outcomes delivered by the RC Project are impressive. The project employed only three staff but has mobilised over 100 volunteers each year to deliver activities and events which have engaged nearly 800 parents and families annually.

The Project has also been successful in levering additional funding from other funders which has enabled it to deliver targeted events for children and young people aged 8-18. As such, the project has provided good 'value for money' for funders.

The success of the project has to a great extent, been as a result of the achievements of the Regional Coordinators in recruiting and supporting volunteers. The Regional Coordinators have been responsive to volunteers' interests and concerns and have adapted volunteering structures and training to meet volunteer needs and ever-changing circumstances. They have trained and supported volunteers to deliver effective events and activities for families with cleft but have also supported volunteers to develop their own skills and confidence and made volunteers feel valued. As a result, they have a high retention rate for volunteers.

Critical success factors in the design and delivery of the project

The Regional Coordinator role

While volunteers have been central to the delivery of the project, the Regional Coordinator role is the critical component in the model. As demonstrated during the staff vacancy in the East of England Region in Year 1, the level of activity was significantly reduced in the period when volunteers did not have support, and some volunteers gave up their volunteering role in this period. This highlights the critical role of the RC in the delivery model.

Through the activities of the RCs, CLAPA has levered hundreds of hours of volunteer input to the delivery of services for people affected by cleft. In year 3, (2019-20) volunteers provided nearly 600 hours of time in the delivery of services for families affected by cleft which supported nearly 800 parents, siblings and family members. However, the Regional Coordinators are the lynchpin in the delivery model. Without this staff role, CLAPA could not mobilise the enormous volunteer effort.

On-line networking

While the delivery of events (which bring families together and enable peer support) has been central to the success of the model, the RC Project has also maximised the use of social media to extend the reach and depth of peer support networks.

At the local level, Regional Coordinators set up closed Facebook Groups for local groups. While these were initially set up to disseminate information to local groups and to allow people to 'stay in contact' between events, feedback from parents demonstrates that the Facebook Groups have become virtual peer support networks, with users frequently commenting that they provide access to 'advice and support from other people who are further along the cleft journey'. Additionally, people from more rural and remote areas who have more difficulty in getting to events have commented that the Facebook groups allows them to participate in the 'cleft community'.

Challenges in the design and delivery

Different levels of activity in different regions

The differences in the delivery infrastructure (the differences in the number of volunteers and volunteer interest and capacity) across the regions has resulted in different types of activities and different levels of activity in different regions. For example:

- In the Central Region volunteers delivered parent support groups (previously known as Happy Faces Groups) but there were no Happy Faces Groups in the South.
- Volunteers in the South Region delivered more family days and events which have engaged large numbers of families but provide a less intensive level of support.

The dependence on volunteers has posed challenges for the project in terms of planning activity levels and setting targets.

Impact of staff vacancy

The critical role of the Regional Coordinator is highlighted. There was a 6-month staff vacancy in the East Region in Year 1.

During the staff vacancy, volunteers had little support, so there were very few events delivered. Some volunteers became inactive without support from the RC and so the number of active volunteers fell away. Even after the post was filled in February 2018, it took some time to rebuild the levels of activity, as it takes time to rebuild relationships with existing volunteers and to recruit new volunteers.

The staff vacancy has impacted on the achievement of some activity targets due to lower level of activity in East Region.

Challenges in engaging and supporting volunteers

Although CLAPA has a number of very long-term and experienced volunteers, the Regional Coordinators have, at times, struggled to recruit new volunteers.

- The challenges in engaging volunteers reflects broader trends affecting the voluntary sector, with volunteer numbers falling and people often less willing to take on formal roles and responsibilities.
- The Regional Coordinators Project has also struggled to engage volunteers in formal training days. Feedback from volunteers highlighted that volunteers were often 'busy people' (work and family commitments) and found it difficult to give up their weekends to attend training.

Responses to the challenges

The RC Project has demonstrated an innovative response to the challenges of engaging and supporting volunteers.

- **Review of volunteering structures**

The RC Project led an organisation-wide review of volunteering structures. Regional Coordinators found that many people were interested in 'giving something back to CLAPA', but that people were less interested in engaging in the formal governance structures associated with branches.

The RCs developed new volunteering structures which dissolved branches and set up more flexible structures. These structures are less bureaucratic and enable volunteers to engage in a different way – there are events groups for those volunteers who are interested in delivering events, but also more flexibility to provide opportunities for people to volunteer in one-off occasions (helping at events, etc). The branch review was led by the RCs but has influenced CLAPA structures /engagement with local groups at a national level.

- **Review of recruitment**

The challenges in engaging volunteers (and the variability in capacity to deliver activities and services across the regions) has also resulted in changes in the volunteer recruitment practices. At the end of year 2, the RCs piloted a more targeted recruitment campaign, focusing on recruitment of volunteers with specific skills or experience to fill specific roles (e.g. recruitment of parent supporters with lived experience of specific conditions). This proved successful in increasing the number of volunteers and the 'fit' of volunteers.

- **Review of volunteer training**

One of the successes of the project has been the high quality of training and support provided by the RCs which has ensured that volunteers have the training, support and encouragement to deliver activities. Volunteers report that they feel valued and this has resulted in high rates of volunteer retention.

Training of volunteers has been critical to ensuring that volunteers have the skills and confidence to deliver, and all volunteers receive induction training and regular refresher training. However, the RC project has experienced challenges in getting volunteers to attend face-to-face training due to the time pressure on volunteers. Training was usually held in a central location to cut costs, and at weekends when volunteers, many of whom are parents have other commitments.

The RC Project has explored and developed alternative methods to make training more accessible to volunteers (on-line training and one-to-one training by RCs). The Project also piloted shared training with another charity (Rett UK) to cut the overhead costs of training delivery. These developments have not only benefited the RC Project but have influenced the approach to volunteer training and development within the whole organisation.

Appendix 1: Revised outcomes

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 a 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 their child	Parents/carers have increased confidence in supporting their child with issues related to cleft	Year 1, Year 2, and Year 3	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
	Parents/carers have access to a	Year 1, Year	Parents/ guardians: 65	Parents/ guardians: 58	Parents/ guardians: 65	Parents/ guardians: 58	Parents/ guardians : 65	Parents/ guardians: 58	Parents/ guardians: 174 (out of 195)

	local support network	2, and Year 3							TOTAL: 174
	Parents/carers 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