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# Evaluation of CLAPA RC Project

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Report on year 1

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Arrivo | Consulting

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# Introduction

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 2018 CLAPA was awarded a 3 year grant from the Big Lottery Fund for its Regional Coordinators Project. The funding enables CLAPA to employ Regional Coordinators in three regions in England. The Regional Coordinators develop and deliver activities in each region aimed at supporting individuals affected by cleft.

## Purpose of the report

The Regional Coordinators (RC) Project has been awarded funding for 3 years from the Big Lottery Fund which runs from 2017 to 2020. This is the evaluation report from the first year of operation, which covers the period April 2017 to March 2018. The report provides:

- a review of the activities and outputs delivered in the first year of the RC Project, and comments on the extent to which the project is on target to achieve its activity targets
- reviews the outcomes to date and comment on the extent to which the project is likely to achieve its outcomes targets
- identifies the learning from the project to date and identified the issues and challenges which have impacted on the capacity of the project to deliver its anticipated outcomes.

## Methodology

The methodology for the study has included:

- Review of the Big Lottery Fund application to identify the key activities, outputs and outcomes which were expected from the grant funding,
- Interviews with key staff members responsible for design and delivery of the project,
- Development of an evaluation framework which underpins the evaluation of this project,
- Development of tools to gather evaluation data from beneficiaries,
- Analysis of evaluation data, and
- Collection of qualitative information (examples and case studies etc) to demonstrate the impact of involvement on beneficiaries.

## What has the project delivered?

This section reports on the key activities delivered during the first year of operation and comments on progress towards targets.

### Description of the delivery model

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

The role of the RC is to develop and deliver activity which creates opportunities to bring together people affected by cleft (children and young people, adults and parents of children with cleft). These opportunities serve to reduce isolation, enable people to share experiences and learn from each other and develop supportive peer networks.

RCs directly deliver services and activities, but much of the activity is delivered through a network of volunteers, so a significant element of the RC role involves recruiting, training and supporting volunteers.

RCs also work with NHS Cleft Teams in their regions to improve access to services for people with cleft.

They also raise awareness of cleft, directly or by supporting volunteers to deliver awareness-raising sessions in communities.

### How the activities deliver the project outcomes

The project aims to deliver two key outcomes:

**Outcome 1: Children, young people and adults affected by cleft lip and/or palate (cleft) are more able to cope with cleft-related challenges**

**Outcome 2: Parents/guardians of child(ren) with a cleft feel less isolated, more able to cope, and more able to support their child**

This section describes how the project activities deliver outcomes for:

- Children and Young People
- Adults
- Parents and guardians

#### Children and young people

CLAPA was successful in leveraging in additional funding from Children in Need to deliver a range of activities aimed at engaging children and young people.

This funding has enabled CLAPA to deliver:

- 5 Family days
- 4 Activity Days
- 1 Residential Weekend
- 3 meetings and a residential weekend for the Children and Young People's Council (CYPC)

## Family Days

Family days are aimed at parents and families with young children (mostly under 8). While these events are attended by entire families, and offer opportunities for parents to meet and network, the days also offer opportunities for children to meet other children with cleft and for siblings to meet siblings from other families affected by cleft. Survey responses showed that parents' motivations for attending family days were often around the opportunity for their children to meet other children with cleft.

*"Showing [child's name] other children with cleft"*

*"To meet other children with cleft"*

69 children and young people attended Family Days.

- Family days are aimed at families with young children and 57 of 69 attendees were under 8 years old

## Activity days/residentials (aimed at 8-18 year olds)

Activity Days (and residential weekends) are offered for children and young people aged 8-18 with cleft. These opportunities are aimed at reducing isolation and building networks so that young people share experiences with other children who encounter similar issues in their lives, learn from each other and build their confidence and capacity to deal with the challenges in their lives.

*"I always thought I was different, but I now know that there are other people out there like me."* Young person age 9, following attendance at Activity Day

*"Thank you for this opportunity you give young people like [X]. The confidence she gains from being around people who understand her life's journey is immeasurable. She had a great day!"* (Parent of young person following attendance at Activity Day)

- 46 children and young people attended activity days/residentials
- The age range of children attending these events is shown below
- Of the 46 attending, 33 said they had some previous involvement with CLAPA and 13 were completely new to CLAPA.

AGE	8 to 9 years old	10 to 15 years old	16 to 18 years old	TOTAL
NUMBER ATTENDING	18	27	1	46

## Children and Young People's Council (CYPC)

The CYPC is the national representative group of young people born with a cleft. The CYPC informs the development of CLAPA services for young people and members of the CYPC have also been involved in consultations on service development for young people with cleft and the development of resources for other young people with cleft.

There are currently 13 members of the CYPC, aged between 9 and 18 years old. These young people have been involved in CLAPA for between 6 months and 5 years.

The group meets 3 times a year for business meetings and attend an annual residential weekend, and therefore this group of children and young people have a greater level of engagement with CLAPA.



**CYPC members at weekend residential**

## **Other key achievements in first year**

### **Creating better access to information for young people with cleft**

Young people on the CYPC have written an information pack for other young people with cleft, providing advice and guidance to help children on their 'cleft journey'

### **Extending peer support and providing development opportunities**

CLAPA identified that many of the older young people were keen to 'give back' by sharing their experiences with younger children. As a result, CLAPA has developed a peer support programme and five young people are being trained as Young Peer Supporters. As a result, CLAPA is extending the reach of peer support for young people and is also providing opportunities for young people to develop their skills and confidence as Peer Supporters.

### **Preparing young people for the world of work**

CLAPA has leveraged other support for young people. A private sector organisation with HR experience delivered a 'workskills' event for young people (aged 16-19) with cleft. The event was aimed at building skills and confidence for the workplace and included information and advice on CVs and interview technique. 6 young people attended.



Feedback from 18-year-old who attended the workskills day.

*I enjoyed meeting other teenagers with clefts as in my day to day life I don't know any. Through chatting with them it was good to find out that they were struggling with some similar things to me.*

*The group exercise was the part of assessment days that I was most worried about. However, on the work skills day I found that it was quite enjoyable. It really improved my confidence and now I'm not so worried about any future assessment days I may attend. I also liked how we also went over common mistakes (e.g. running of time) and I think getting the marking criteria was also really useful because it means I can identify the skills I need to work on.*

*I think my CV has improved and I understand more about what employers are looking for, so I feel more confident about applying to jobs.*

*Having done the workskills day, I feel more confident about attending a training day on my own.*

## Adults

The key activities aimed at providing support for adults are:

- Peer support service – a volunteer run peer support services for adults with cleft
- CLAPA supports an Adult Voices Council, a group of adults affected by cleft who have worked with CLAPA to explore services for adults. The group is volunteer run, so has limited capacity to deliver services directly, but has developed a Facebook page which has provided a virtual network for adults affected by cleft.

### Peer Support Service

37 people were matched with a volunteer peer supporter through the service (this figure relates to the period November 2016 when the service was relaunched to April 2018).

### Key Achievements:

CLAPA is working toward the APS standard to ensure the quality of the Parent and Peer Support Services. (Assessment in April 2018)

## Parents and guardians

### Parent Support Service

The Parent Support Service is a peer mentoring service which matched parents with another parent (volunteer) who has had experience with similar issues and challenges. This can involve dealing with a pre-natal or post-natal diagnosis of cleft, feeding a baby with cleft, preparation for a child's operations etc.

- 92 Parents have contacted the service since its relaunch in November 2016.
- The RC Project has matched 31 parents with a volunteer supporters in year one.

## Happy Faces Groups

Happy Faces Groups are local meet ups for parents with babies and small children which provide peer support for parents. Happy Faces Groups are delivered by volunteers supported by RCs. In some regions, Cleft Nurse Specialists from the Cleft Teams attend Happy Faces Groups to provide ongoing support/contact with families.

RCs have supported volunteers to deliver 17 Happy Faces Group meet-ups, providing peer support for 75 parents and their children.

## Family days and other local events

CLAPA creates a range of opportunities for families to meet up at the local level

- **Family days**

Family days are aimed at parents and families with young children (mostly under 8). The purpose of the events is to provide opportunities for families affected by cleft (and sometimes expectant parents) to come together, to get to know each other in an informal environment and to share experiences provide informal support to each other.

Family Days also offer opportunities for children to meet other children with cleft.

*"The family days are supportive not only to parents for support from other parents, but also for the children as they mature to give them opportunities to play with and talk to other children with a cleft lip and/or palate" (Parent, from survey response)*

*"I just wanted to thank you for organising the day out recently. We had a lovely time, and I didn't realise how much I needed it until I was there. I've found some of our recent difficulties with X's speech and hearing a bit isolating (as my friends find the subject uncomfortable), so it was nice to feel reassured by others going through the same journey and come away feeling a more positive about it all."*

The RC project has delivered 5 Family Days. RCs directly deliver these activities, but volunteers are frequently involved in the delivery of these events.

- **Family focused events**

Branches organise a range of events (social, fundraising etc) which provide local opportunities for parents and families to meet and support each other. These are organised by volunteers and supported by RCs. Parents reported their reasons for attending as:

*To meet people on the same journey as us to provide insight if they're ahead.*

*Also, for my eldest to understand there are other children as special as her sister.*

*Its lovely to be around people who have shared the same or similar experiences – to show the girls they don't look different from everyone else*

The power of providing opportunities for families affected by cleft to meet up is demonstrated by the parent feedback:

*CLAPA has made a world of a difference – coming to events like this Christmas party means relaxing and not having to explain – to be included and understood without a lengthy explanation!*



*It's lovely to meet people who understand the small things. It makes a lonely place not lonely at all*

The RC Project has supported volunteers to deliver 10 events to bring parents together. In total 850 people (children, parents, siblings and families of children affected by cleft) have attended events delivered through the project.

### **Virtual networks**

The RCs have also set up regional Facebook pages. These are used to publicise local events and engage with families but have also developed as a virtual peer network for many parents.

*"Because we live so rurally and have other children with complex issues we were unable to attend the days but we did gain great support from the FB page"*

## **Other activities**

### **Raising awareness of cleft/improving services for people affected by cleft**

The RCs also work to raise awareness of cleft. They deliver awareness raising talks in schools and communities.

RCs have delivered 9 awareness raising sessions.

This case study highlights an example of involving volunteers in awareness raising and demonstrates how awareness arising can result in improved services for people with cleft.

A lecturer at Birmingham City University contacted the RC in the Central Region. The University delivers CPD for midwives and wanted to provide an input to the programme to improve midwives' knowledge of the impact of cleft lip and palate (on the family as well as the child) and improve knowledge of the services available to families.

The RC supported two volunteers to present to the midwives at Birmingham City University in March 2018.

At the end of the session, midwives were asked to provide feedback on

- The most useful thing they learned in the session
- One thing they will do differently as a result of what they had learned

#### **The feedback showed that midwives had learned about:**

- the incidence of cleft and the associated conditions,
- the impact (emotional impact on children and families)
- the treatment involved (especially the lifelong series of operations)
- the existence of local services to support children and families through the treatment and with the emotional aspects of dealing with cleft

The session was clearly very informative for midwives, all of whom who could identify simple actions they could take to improve services for families affected by cleft.

**Things that they would do differently as a result of the learning:**

- I will get in touch with local cleft lip and palate team for more info and share with health visiting team
- I will provide more emotional support and knowledge and be able to direct parents/families to sources of support
- I will encourage women and families to access available groups that are there for them to use
- I'll be able to inform parents better about CLP and understand their emotions
- Get early feeding support in hospital and community
- Be more informative and also ensure contact details are provided to parents
- Emotional support, find more out, more details of local support
- Refer to helpful links, be honest and make them aware of what it means long term

**Feedback from the volunteer who presented**

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

**What next?**

The lecturer who invited CLAPA to the event now wants to incorporate this input into other train for midwives.

**Supporting people to improve services for cleft**

RCs also ask people affected by cleft to feed back on the quality of services and shape the future of NHS cleft care. They currently support three Patient Partnership Groups (London, Birmingham and Cambridge) and are exploring opportunities to launch new groups.

**Progress against targets**

This section reviews the progress against the targets outlined in the Big Lottery Fund application for year 1.

- Table 1 summarises the key targets and the progress against these targets.
- The 'issues' section provides an overview of some of the key issues which have influenced the delivery of targets.

**Table 1: Progress against targets**

Target outputs	Actual outputs
<b>Develop new branches</b>  2 new Branches established (East of England and East Midlands).	No new branches established <ul style="list-style-type: none"> <li>• The RCs led on a review of the CLAPA branch structure. This has resulted in the development of new functionally based groups in place of the historic branch structure. These will become operational in</li> </ul>

	<p>April 2018 and new groups will be established in the project regions.</p>
<p><b>Deliver local events</b></p> <p>RCs support their Branches to each deliver 2 events in their local area (=16 total)</p>	<p>This target of 16 events was based on the existence of eight branches.</p> <p>There were five branches operating during the year (four branches in South East and one in Central) so the number of events is lower than the target due to the lower number of branches.</p> <p>RCs have delivered 5 Family Days and supported volunteer run branches to deliver 10 other events in the year. These events include:</p> <ul style="list-style-type: none"> <li>○ A fun run</li> <li>○ Christmas events</li> <li>○ Summer picnics</li> <li>○ Fundraising events</li> </ul> <p>There have been over 850 attendances at these events in total (this number includes parents and families of children affected by cleft, as well as adults and children with cleft.</p>
<p><b>Training volunteers</b></p> <p>Target to deliver:</p> <ul style="list-style-type: none"> <li>• 1 national Peer Supporter Training Day,</li> <li>• 2 national Parent Supporter Training Days,</li> <li>• 3 regional Branch/Clinic Volunteer Training Days, and</li> <li>• 3 regional Volunteer Development Days</li> </ul>	<p>Following consultation with volunteers, the training plan was changed as volunteers identified that national training days were difficult to get to /took up too much time to attend.</p> <p>RCs developed 3 regional training events (one in each of the region) to better meet volunteer need</p> <p>However, it was difficult to secure attendance of volunteers. Only 11 volunteers in total attended over the 3 regional training days.</p>

<p><b>Supporting volunteers</b></p> <p>Targets:</p> <ul style="list-style-type: none"> <li>• RCs carry out 2 supervisions per year with 100 current volunteers (200 supervisions)</li> </ul>	<p>The total number of volunteer supervisions carried out is 100.</p> <p>The target for volunteer supervisions was over-estimated:</p> <ul style="list-style-type: none"> <li>• The total number of volunteers in the year has been lower</li> <li>• Not all volunteers need two supervisions per year (some volunteers have several roles and have one supervision to cover 2 or more volunteer roles).</li> </ul>
<p><b>Recruit new volunteers</b></p> <ul style="list-style-type: none"> <li>• Recruit and induct 35 new volunteers (total) across the year</li> </ul>	<p>The RCs have recruited and inducted 21 volunteers:</p> <ul style="list-style-type: none"> <li>• There are fewer volunteer inductions in the East due to staff vacancy, but it would appear that the number of volunteers which could be recruited and supported was overestimated.</li> </ul>
<p><b>Happy Faces Groups</b></p> <p>RCs support 15 Happy Faces groups to run regular meetings across the year for approximately 4 families per group</p>	<p>A total of 6 Happy Faces Groups have operated throughout year 1.</p> <p>2 new groups were developed during the year (one in Central and one in south East)</p> <p>Some groups meet monthly while others are less frequent. In total there were 150 family attendances at Happy Faces Group meetings.</p> <p>(NB some families will have attended more than one meeting)</p>

## Issues affecting delivery of targets

### **Staff Vacancy**

One of the three RCs left their post in August 2017. The post was advertised immediately, but the recruitment process did not result in an appointment. The post was re-advertised and filled on the second round of recruitment. The new post holder started in February 2018. The five-month period of vacancy has reduced the level of activity in the East Region.

### **Review of Branch structure**

Over the period of the grant, CLAPA has reviewed its local branch structure. Following a national consultation, a decision was taken to disband branches and set up local groups. Branches were generic in nature, but the groups will be functional e.g. events groups, fundraising groups. The aim of the restructure is to create more opportunities for more people to engage at a local level and to remove some of the barriers to engagement.

As of April 2018, branches have been replaced by functional groups in local areas.

### **Volunteer infrastructure in each of the Regions is different**

The delivery of events and activities rely on the efforts of CLAPAs network of volunteers. In some of the regions, there were established branches and a network of volunteers who have delivered a range of activities. In other regions the infrastructure is less developed, with no branches/groups and fewer existing volunteers. In these areas, RCs need to build the volunteer base to support the delivery of local activity.

### **The activities delivered are dependent on volunteer availability/interest**

Although CLAPA set targets for the delivery of some specific types of activity (for example, a target to develop 15 Happy Faces Groups) the capacity to deliver these activities depends of finding volunteers who are interested/able to deliver these activities. For example, South East Region has a strong infrastructure through the branch structure, but had no Happy Faces Groups, as there has been less interest from volunteers in delivering this service. The RC was successful in setting up one Happy Faces Group in the region this year.

## Has the project achieved its outcomes?

The Regional Coordinators Project has two key outcomes:

**Outcome 1: Children, young people and adults affected by cleft lip and/or palate (cleft) are more able to cope with cleft-related challenges**

**Outcome 2: Parents/guardians of child(ren) with a cleft feel less isolated, more able to cope, and more able to support their child**

This chapter reviews the progress toward the delivery of these outcomes in year 1 for:

- Children and young people
- Adults born with cleft
- Parents and guardians of children with cleft

### Outcomes for children and young people

Children, young people and adults affected by cleft lip and/or palate (cleft) are more able to cope with cleft-related challenges

Indicators	Project Target (3 years)	Year 1 targets
Children, young people and adults report having access to a local support network	187 children and young	63
Children, young people and adults report increased knowledge of mechanisms for coping with cleft-related challenges	219 children and young people	73
Children, young people and adults report being more able to cope with cleft-related challenges	276 children and young people	92

CLAPA offers different opportunities and varying levels of engagement for children and young people at different stages in their lives. As a result, the outcomes delivered at these activities are different. The following section considers the outcomes delivered for

- Children under 8 (primarily engaged in Family days)
- Children and young people aged 8-18 engaged through Activity Days and residential
- Children and young people who are involved in the Children and Young People's Council, who have a high level of engagement with CLAPA, often over a number of years.

#### Children under 8: Engaged through Family Days

69 children and young people have attended Family Days. The majority of children are under 8 years old. Children said that they 'had fun' and 'made friends' at the events. We asked parents what their children got out of attending family days.



All of the responses identified the importance of meeting with other children with cleft and being able to find out about the cleft journey from other children who has had similar experience (e.g. operations).

*"Seeing other children with clefts, making friends"*

*"Meeting and socialising with other children who are cleft affected"*

*"To meet similar age children with experiences of operations"*

*"To meet with a child who has just had an operation that mine is due to have"*

Due to the age of the children (57 of 69 attendees were under 8 years old) and the relatively light touch engagement, we would not expect that these children will identify as 'having access to a support network' or 'increased knowledge of mechanisms for coping with cleft-related challenges' but the feedback from parents demonstrates that engagement in Family days has resulted in children making preliminary steps toward achievement of these indicators.

### Children 8-18: Activity Days / residentials

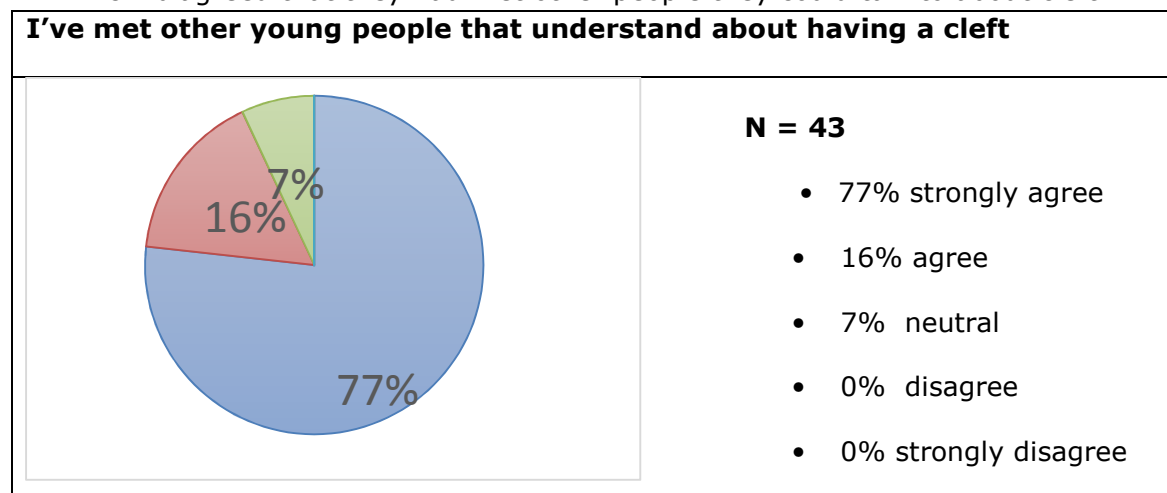
This section identifies progress toward the outcome for children and young people who have attended Activity Days and residentials.

- 46 children and young people between the age of 8 and 16 attended Activity days or residentials.
- Of the 46 attending, 33 said they had some previous involvement with CLAPA and 13 were completely new to CLAPA.

These results are based on a survey completed by children and young people on the impact of their involvement in CLAPA.

### Indicator 1: Children, young people and adults report having access to a local support network

- 93% agreed that they had met other young people who understood about living with cleft
- 81% agreed that they had met other people they could talk to about cleft



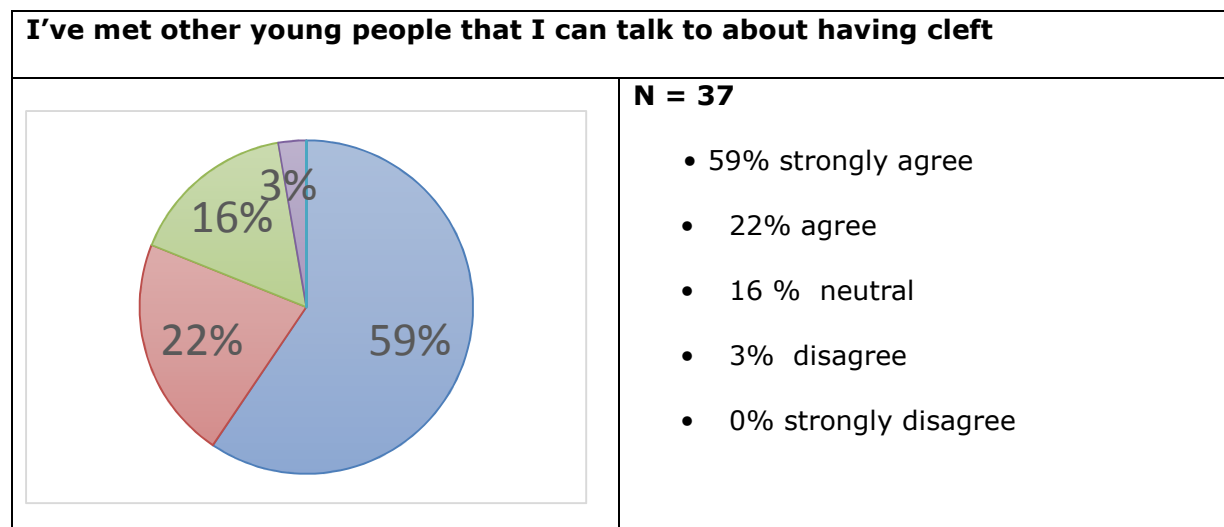
In an open question 'what was the most important thing you got out of coming along to this event?' 18 of the 36 comments related to making friends with cleft/who understood cleft.

*"I loved meeting other people because I made new friends and learnt that other people are the same as me"*

*"Making friends that understand what I have"*

Five of the 36 comments directly referenced 'not being the odd one out' or the realisation that they were not the only person with cleft.

*"[That] I'm not the only one in the world with a cleft"*

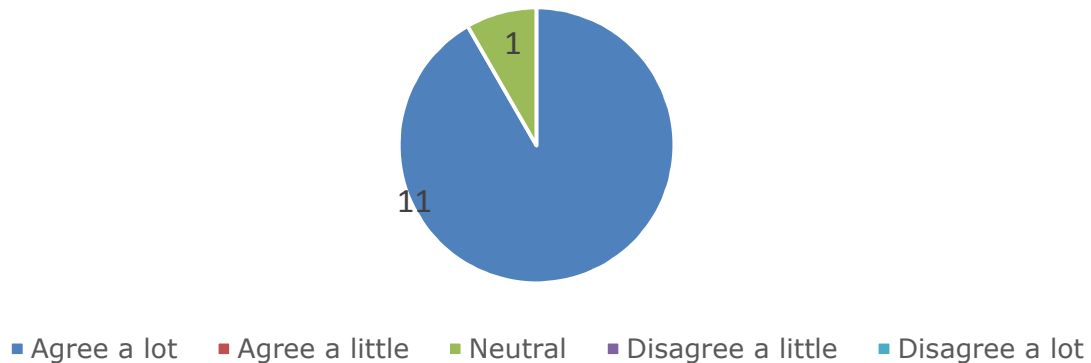


**Indicator 2: Children, young people and adults report increased knowledge of mechanisms for coping with cleft-related challenges**

There is less evidence for this indicator, as activity days are social/activity focused events which do not directly offer opportunities for children and young people to learn about ways of coping with cleft. However, residential events provide more time for young people to talk to each other, but also include activities which encourage sharing of experiences.

- Of 12 children and young people who attended a residential event, 11 strongly agreed that they had learned more about the ways that other young people deal with having cleft.

I understand more about the ways that other young people deal with having cleft

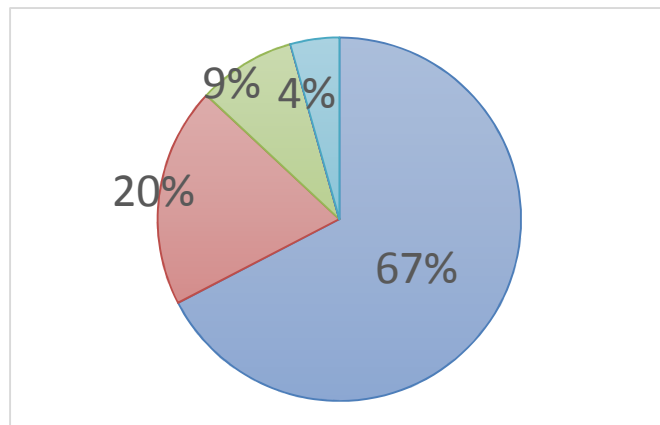


**Indicator 3: Children, young people and adults report being more able to cope with cleft-related challenges**

We have used increased confidence as a proxy for this indicator.

- 87% reported that they felt more confident

**I feel more confident about myself**



**N = 46**

- 67% strongly agree
- 20% agree
- 9 % neutral
- 4% disagree
- 0% strongly disagree

In response to an open question about what they felt more confident about, children and young people identified two key themes:

- **feeling more confident about having a cleft**  
*"I feel more confident about my face"*  
*" I feel more confident about my cleft lip and palate"*
- **improved social confidence**  
*"I feel much more confident to make new friends"*  
*"Speaking to others about my cleft lip and palate "*

As young people at activity days had participated in a range of adventurous activities, some also identified that they felt more confidence in their physical skills (climbing, doing a front flip, doing the zip wire, doing something for the first time). Developing physical confidence also helps to build self-belief and self-esteem among children with cleft. An 11 year old comments that the most important thing s/he got out of the day was .....

*"..... learning that you can do everything that everyone else can do"*

We also gathered feedback from parents on the impact on their children of involvement in Activity Days

*"My son attended an activity day and he loved it. He is very insecure about his appearance so meeting with others helped him so much! He came out adamant that he would go to as many meet ups as possible!"*

*"[child's name] LOVED today..... I forget she feels different from other kids because of her cleft as we don't notice it, but she said it was great to be with other children like her and she's looking forward to getting to know them better at future events. Thank you again"*

*"[Child's name] has been a lot more confident in his self [since attending] and wants to attend more activities like this and I hope they make him feel more comfortable inside"*



**Children and young people after abseiling and zipwire adventure**

### **Children and Young People's Council (ages 9-18)**

We asked young people what they got out of being involved in the CYPC. Involvement has clearly served to build their confidence and wellbeing.

*"Having fun"*

*"Not feeling different"*

*"I get a lot of things out of the CYPC, it makes me happier"*

*"Meeting new people"*

*"It's fun and makes me feel better"*



**Members of the Children and Young People's Council having fun at a residential weekend.**

Their involvement on influencing service design and delivery has also increased their belief that they can make a difference.

*"Your voice gets heard and its reflected on CLAPA"*

A key outcome of bringing children and young people together is that they form supportive relationships. They exchange advice and tips on dealing with cleft (from confidence and tips on dealing with bullying at school to practical advice about dealing with operations and recovery).

Many of the young people are also motivated by supporting others with cleft and that they get a lot out of supporting others,

*"Helping others who are younger with operations I've had and that they haven't had yet"*

*"Getting to know other people with a cleft and knowing that my experience could be useful to someone else with a cleft"*

As a result, CLAPA has developed a peer support programme for young people. This will be piloted I year 2. Five young people from the CYPC have volunteered for training as peer supporters.

### Evidence of Outcomes

Young people who are involved in the CYPC have a much greater level of engagement with CLAPA, and it is with this group that we anticipate the most significant change.

- Some of these young people have been involved over a number of years.
- The group meet 3 times per year and have a residential weekend, so the young people have more opportunities to meet and develop peer networks.

We have we collected survey data from the young people and also collect feedback from parents on the impact of their child's involvement.

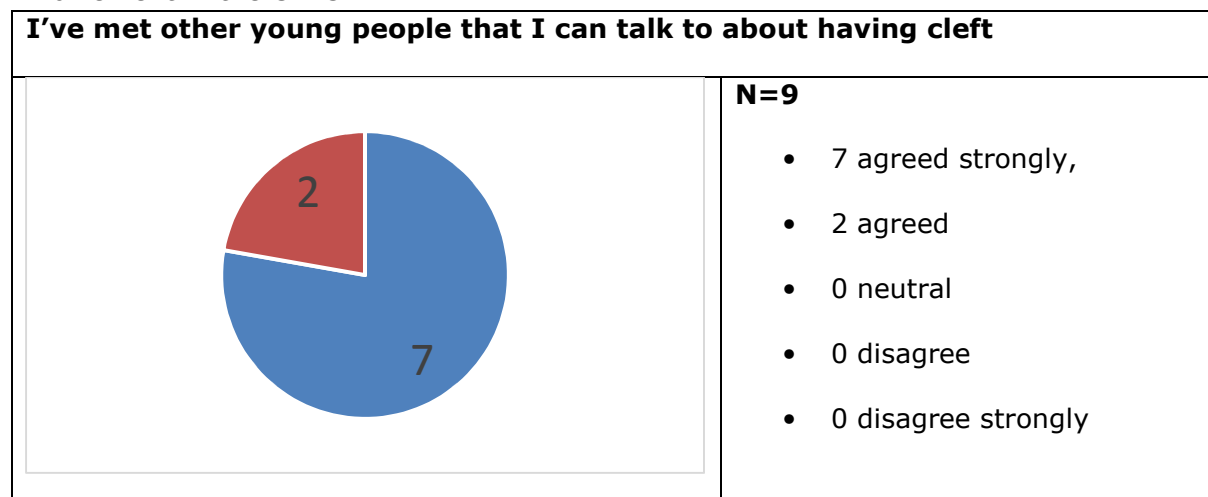
The following data is based on responses from nine of the CYPC members.

- The young people were between 11 and 16 years old
- Three had been involved in the CYPC for less than six months
- 6 had been involved for two years of more.

Please note the figures quoted are whole numbers (not percentages) due to the small number in the sample.

### Indicator 1: Children, young people and adults report having access to a local support network

All of the young people had met people that they could talk to about cleft through their involvement in the CYPC





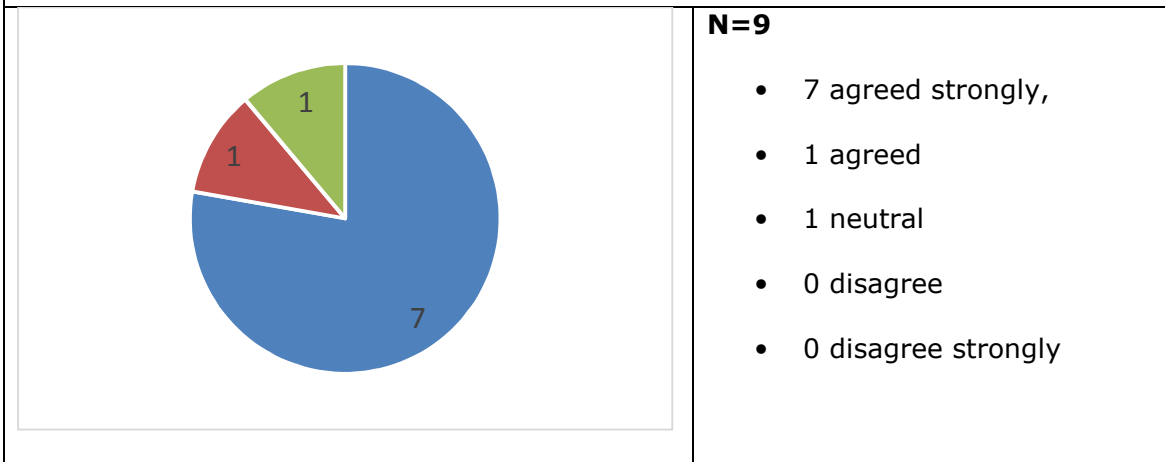
**Indicator 2: Children, young people and adults report increased knowledge of mechanisms for coping with cleft-related challenges**

- 8 out of 9 young people have learned things about dealing with cleft related challenges (1 neutral)

Young people said that they had learned

- *“Sharing tips and stories”*
- *“[I’ve learned] what to do and what to expect when having an operation and other ways to look at it”*

**I’ve learned things about the ways other people deal with having cleft that are useful to me**

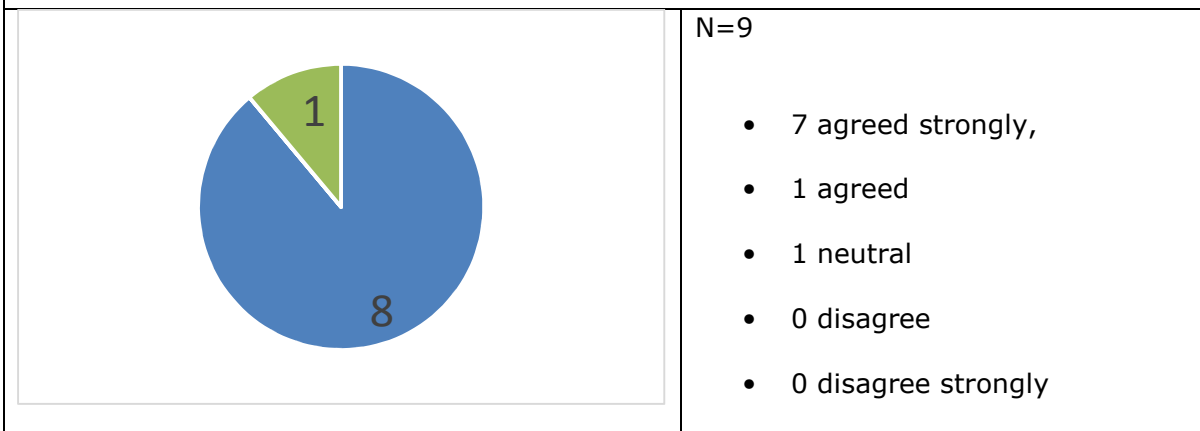


**Indicator 3: Children, young people and adults report being more able to cope with cleft-related challenges**

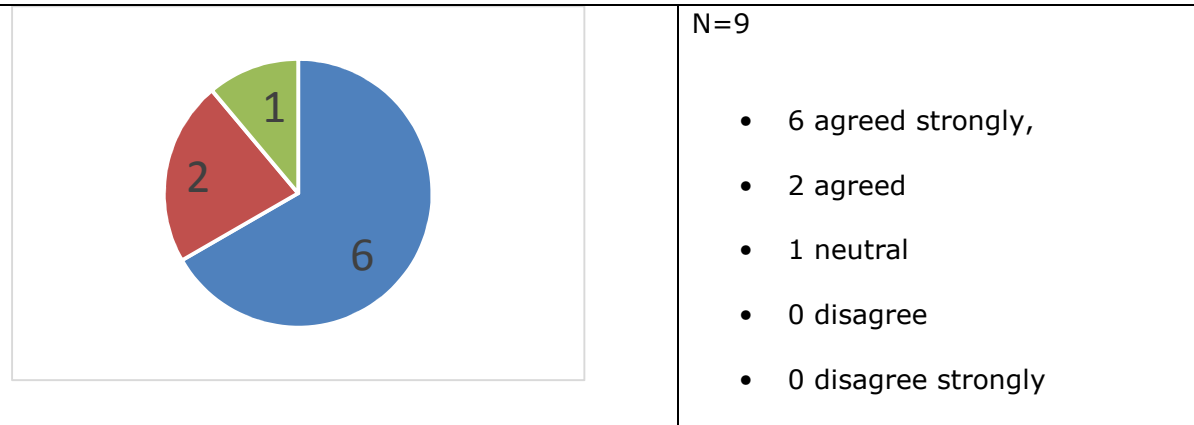
We asked young people if they felt:

- 8 of 9 said they felt more positive about themselves and what they could achieve
- 8 of 9 said they were more positive about dealing with cleft related challenges.

**I feel a bit more confident about myself and what I can achieve**



### I feel more positive about dealing with cleft



Parents provided feedback on the impact on their child of involvement in the CYPC.

*"Being a member of the council is a hugely positive experience for my son. He regards all the members as his friends and they really have become a support network. It is fantastic that the council has members covering a wide age range so that there is always someone on hand to offer advice and support to a child at a different stage of their cleft journey, whether that be dealing with issues around bullying or upcoming surgery."* Parent of CYPC member

*"It helps him put his own cleft related experiences - whether that's at home, school, with friends, surgery, into perspective. He can ask specific questions to those who have experienced something similar and compare their answers to his own experiences, and if he has any worries he can ask those older than himself what to expect. He feels its helped him get to know what will happen in the future"* Parent of CYPC member.

## Outcomes for Adults

Indicators	Project Target	Year 1 targets
Children, young people and adults report having access to a local support network	18 adults	6 adults
Children, young people and adults report increased knowledge of mechanisms for coping with cleft-related challenges	15 adults	5 adults
Children, young people and adults report being more able to cope with cleft-related challenges	18 adults	6 adults

### Peer Support Service

6 people were matched with a volunteer peer supporter through the service over the period.

We have not collected additional evaluation data from adults (due to the very small numbers) but used the feedback that CLAPA collects through the peer support follow-up system.

*"It's great to know this service exists. CLAPA were so quick to get back to me after I made contact and so quick to match me with a peer supporter. I am very grateful."*

*"It was extremely helpful"*

## Outcomes for Parents and Guardians

**Parents/guardians of child(ren) with a cleft feel less isolated, more able to cope, and more able to support their child**

<b>Indicators</b>	<b>Project Target</b>	<b>Year 1</b>
Parents/guardians report increased confidence in supporting their child with cleft-related challenges	150	50
Parents/guardians report having access to a local support network	174	58
Parents/guardians report being more able to cope with cleft-related challenges	237	79

### Parent Support Service

We have not collected independent survey data from parents who receive support, as the many of parents are in crisis when they approach the service. However, RCs have collected feedback from parents (when it is appropriate to do so) which demonstrate the value of the service.

*"After the initial diagnosis of our newborn, it was nice to have someone I could contact who had been through something similar."*

### Happy Faces Groups

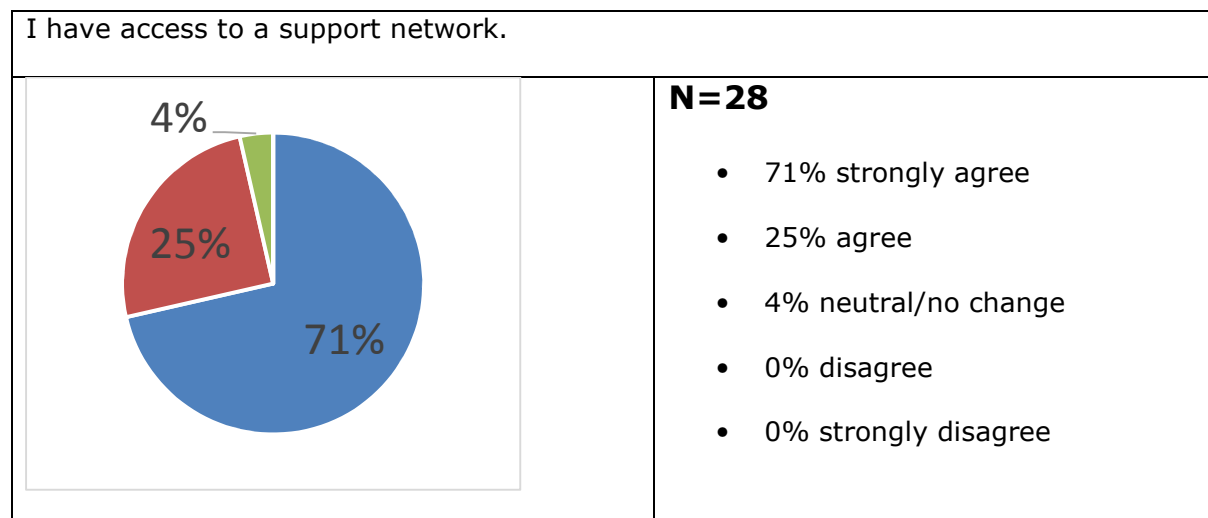
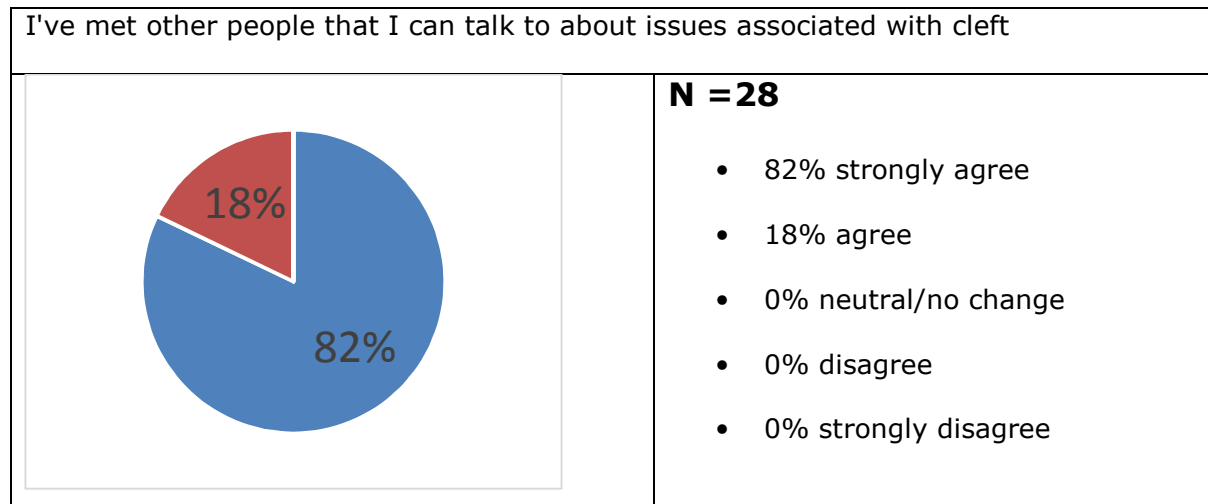
Happy Faces Groups are peer networking groups for parents of new babies and younger children.

We carried out survey to explore the impact of involvement in Happy Faces Groups. The following results are based on responses from 28 parents. Of the 28 respondents:

- 8 were attending the HFG for the first time
- 12 had attended between 2 and 5 times
- 8 had attended more than 6 times

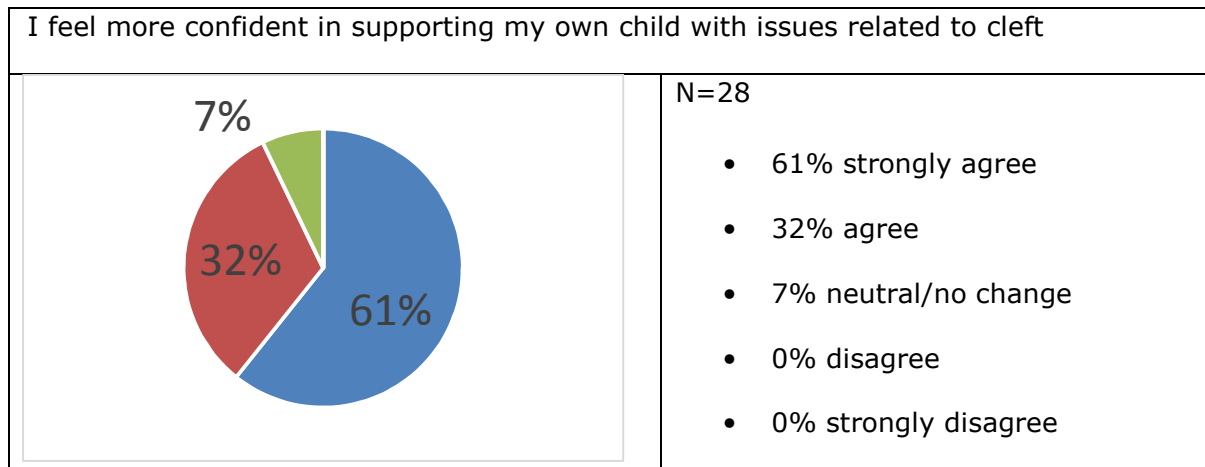
**Indicator 1: Parents/guardians report having access to a local support network**

- **100%** agreed or strongly agreed that had met other people they could talk to about cleft-related issues through the Happy Faces Group
- **96%** agreed or strongly that they had access to support from others in the group (4% reported no change/neutral)



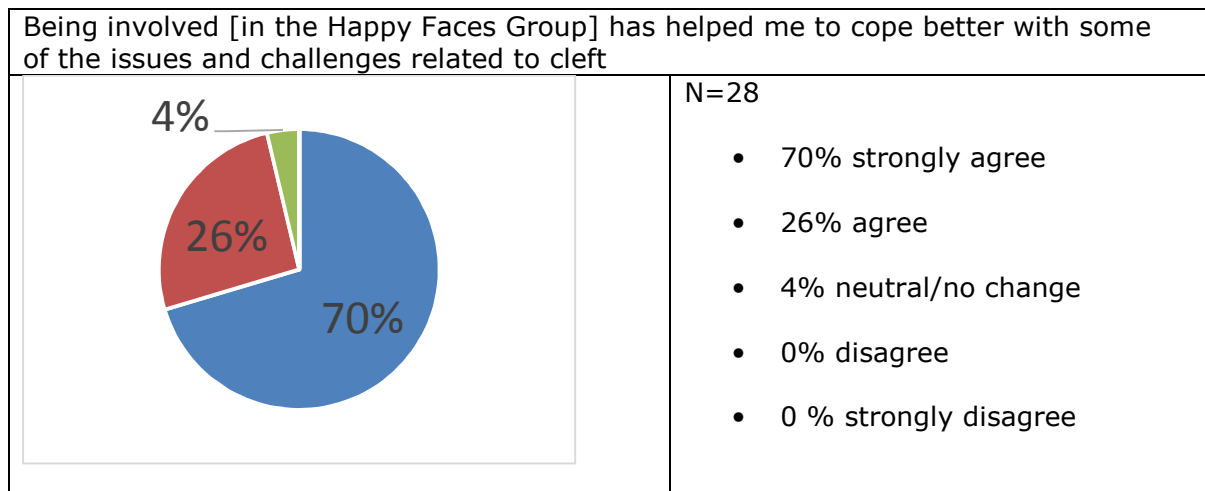
**Indicator 2: Parents/guardians report increased confidence in supporting their child with cleft-related challenges**

- 94% in total felt more confident in supporting their own child with cleft-related issues



**Indicator 3: Parents/guardians report being more able to cope with cleft-related challenges**

- 96% felt better able to cope with cleft-related challenges



The impact of peer support is demonstrated by the comments from people who attend Happy Faces Groups.

*"Before the group I felt quite isolated as I didn't know anyone else who had a child with a cleft. Since joining the group I've met some lovely people who were able to share their experiences and offer great advice."*

*"Happy Faces has been a Godsend. It has been a lifeline for our family, supporting us through the difficult times and celebrating the good times. We have received so much support, advice and guidance from other group members, I*

*genuinely don't know how we would have coped with our son having a cleft lip and palate if it wasn't for this group."*

*"I thought I was abnormal as such for thinking and feeling how I do but with the group I've learnt I'm not. And now I can share my experience with new babies' parents."*

*"I have attended many happy faces events and myself and [child's name] have made many friends and [have a] support network."*

### **Other parent networking opportunities**

We carried out a survey to ask parents about the type of activities they engaged with /level of involvement in activities and the impact of their involvement in CLAPA. 71 parents/guardian responded to the survey.

Surveys responses showed that parents and guardians had very different levels of engagement with CLAPA and that they engaged in a variety of different ways – some have a relatively light touch engagement through attendance at Family Days or other local events (summer picnics, and Christmas events) and links through the Facebook page while others have a high level of involvement and are also involved as volunteers - involvement in local groups (previously branches), as volunteer fundraisers, as Happy Faces Coordinators and parent and peer supporters.

The power of providing social events for parents of children with cleft is demonstrated in the quotes:

*"CLAPA has made a world of a difference – coming to events like this Christmas party means relaxing and not having to explain – to be included and understood without a lengthy explanation! (Parent, survey response)*

*"Being part of a local group, getting support pre and post birth, knowing that events are happening near home has been a great support in raising a cleft child. The East Anglia Facebook group also allowed to share experiences and help other families." (Parent, survey response)*

*"Feel so lucky to have a group of like minded parents and professionals who can support us and help us through emotional challenges. Or simply just to relate. Feel normal. We've thoroughly enjoyed various summer activities and party days. And the Christmas parties too..... The Christmas party was amazing. My children loved it so much. I was also able to link up with some lovely parents and organiser of a local happy faces group and I've been attending since start of 2018 when I can." (Parent, survey response)*

*"My child has gained so much confidence by attending clapa events, he very much looks forward to them. I as a parent feel like I have a great support network." (Parent, survey response)*

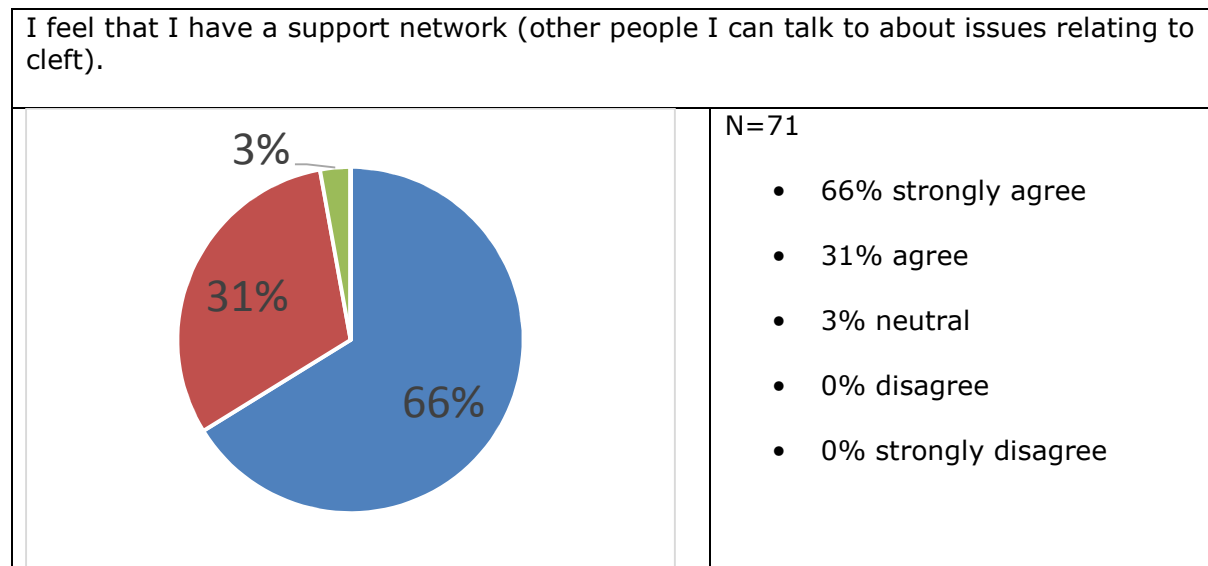
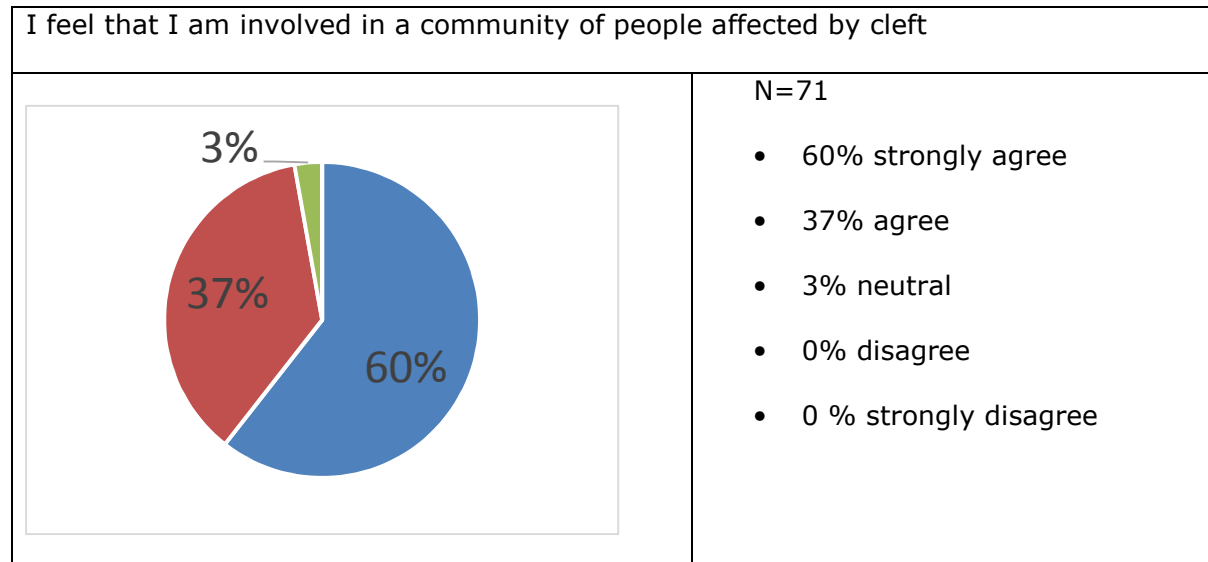


### Evidence of outcomes

The survey asked parents about the impact of their involvement in CLAPA. The following section reports on progress toward each of the indicators

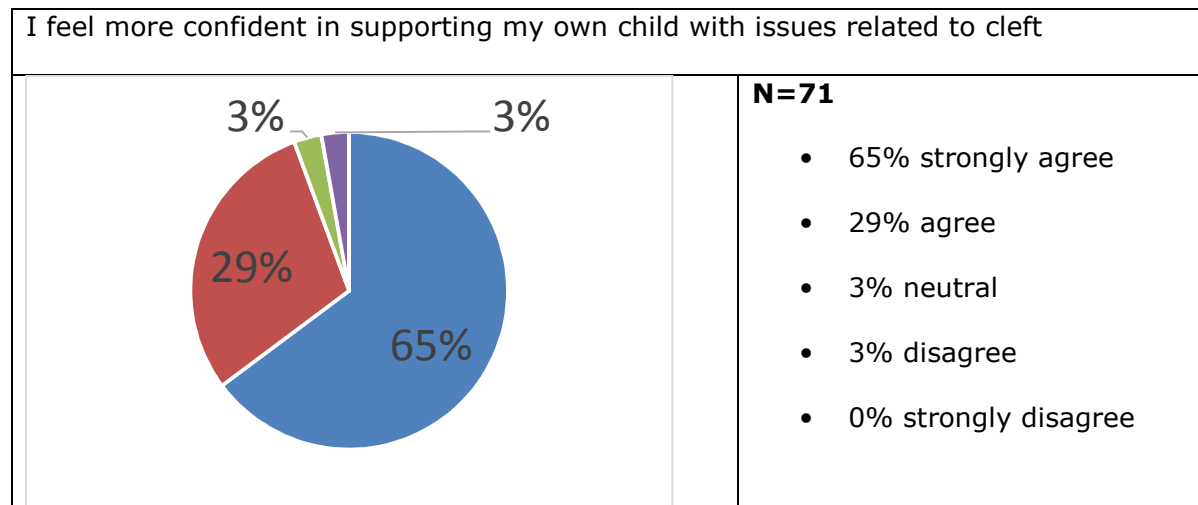
#### Indicator 1: Parents/guardians report having access to a local support network

- 97% of parents felt part of a community
- 97% of parents felt that they had a support network



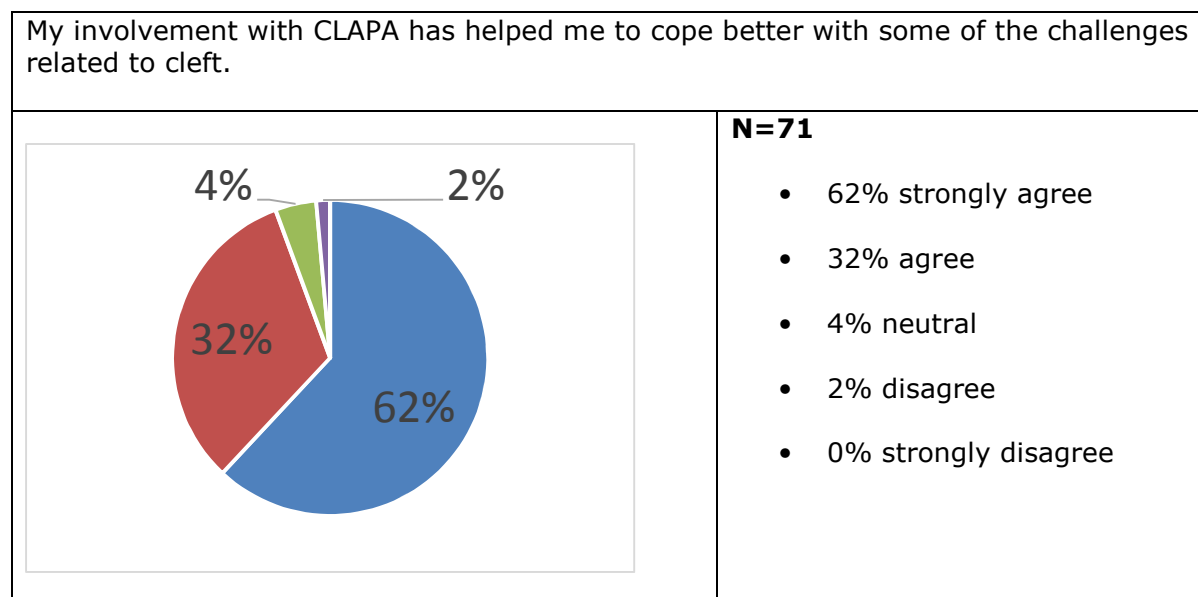
**Indicator 2: Parents/guardians report increased confidence in supporting their child with cleft-related challenges**

- 94% had more confidence in supporting their child with cleft related challenges



**Indicator 3: Parents/guardians report being more able to cope with cleft-related challenges**

- 94% felt better able to cope with cleft related challenges



**Parents comments on the impact of their involvement in CLAPA**

The following is a sample of the comments were provided by parents on the impact of their involvement in CLAPA.

*“Clapa have been an amazing support through my pregnancy, immediately after my son was born (through quickly sending specific feeding bottles), and also as*

*my son is growing up. The family days are supportive not only to parents for support from other parents, but also for the children as they mature to give them opportunities to play with and talk to other children with a cleft lip and/or palate”*

*“CLAPA have been a god send. A community who know what we are going through and can help and advice”*

*“Really helped to talk to parents who've been through the operation and get reassurance that everything will be ok!”*

*“Practical and emotional support from diagnosis onwards has been amazing. Good to be able to speak to others who gave been affected by cleft in children.”*

*“I am not sure I could of coped with our cleft journey, especially in the first 2 years, without the support and help from CLAPA”*

*“CLAPA is an essential charity that brings together people affected by clefts. It allows people to connect with others who have a cleft or are a parent of a child with a cleft. It can be very isolating having a child with a need that is different to the majority of children and CLAPA provides support and guidance on feeding and how to prepare for surgery to name but a few examples. They also fund support group meetings that allow cleft affected people to come together and share knowledge and support to others. It is a fantastic charity.”*

## Conclusions and learning from the project

This chapter provides a summary of the key findings on progress toward outcomes, the issues which have impacted on the delivery of outcomes, and reports on how the Regional Coordinators project has responded to the challenges.

### Progress toward outcomes for children and young people

The table below summarises the progress against the indicators.

<b>OUTCOME</b>		
<b>Children, young people and adults affected by cleft lip and/or palate (cleft) are more able to cope with cleft-related challenges</b>		
<b>Indicators</b>	<b>Year 1 target</b>	<b>Progress in year 1</b>
Children, young people and adults report having access to a local support network	63	<p>69 engaged through Family Days</p> <ul style="list-style-type: none"> <li>Children are too young to report on access to a 'support network'</li> <li>Children and parents report children have 'made friends' demonstrating that children have made first steps towards developing a support network</li> </ul> <p>46 engaged through Activity days/Residentials:</p> <ul style="list-style-type: none"> <li>93% agreed that they had met other young people who understood about living with cleft</li> <li>81% agreed that they had met other people they could talk to about cleft</li> </ul> <p>13 involved in CYPC:</p> <ul style="list-style-type: none"> <li>Of 9 survey responses, all reported having had met people that they could talk to about cleft through their involvement in the CYPC</li> </ul>
Children, young people and adults report increased knowledge of mechanisms for coping with cleft-related challenges	73	<p>69 engaged through Family Days</p> <ul style="list-style-type: none"> <li>No evidence for this indicator</li> </ul> <p>46 engaged through Activity Days/Residentials</p> <ul style="list-style-type: none"> <li>Activity days do not directly offer opportunities for children and young people to learn about ways of coping with cleft, no direct evidence for 34 young people.</li> <li>Of 12 children and young people who attended a residential event, 11 strongly agreed that they had</li> </ul>

		<p>learned more about the ways that other young people deal with having cleft.</p> <p>13 young people involved in CYPC</p> <ul style="list-style-type: none"> <li>• 8 out of 9 young people have learned things about dealing with cleft related challenges (1 neutral)</li> </ul>
Children, young people and adults report being more able to cope with cleft-related challenges	92	<p>69 engaged through Family Days</p> <ul style="list-style-type: none"> <li>• No evidence for this indicator</li> </ul> <p>46 engaged through Activity Days/Residential</p> <ul style="list-style-type: none"> <li>• 87% reported that they felt more confident demonstrating progress toward the indicator.</li> <li>• respondents reported: <ul style="list-style-type: none"> <li>○ feeling more confident about having a cleft</li> <li>○ improved social confidence</li> </ul> </li> </ul> <p>13 young people involved in CYPC</p> <ul style="list-style-type: none"> <li>• 8 of 9 said they felt more positive about themselves and what they could achieve</li> <li>• 8 of 9 said they were more positive about dealing with cleft related challenges</li> </ul>

### Learning and issues for the future

The Regional Coordinators Project has been particularly successful in engaging children and young people affected by cleft. The monitoring data shows that the project and has been reaching new families and engaging new children and young people, building their confidence and developing supportive peer networks through activity days and residential.

The reach of the project has outstripped the targets. The project has engaged over 120 children and young people.

However, 69 of the 120 were children were engaged through Family Days.

- Although we see less direct progress toward the outcomes from Family Days, these events provide an introduction and first step toward further engagement in CLAPA activities. Many children who engage for a first time in family days go on to engage in activity days etc.

The project has engaged 46 young people in Activity Days/Residential

- There is evidence that these young people are making progress toward the indicators

Young people engaged through the CYPC demonstrate strong evidence of achieving the project outcome.

Children and young people who have had a greater level of engagement (through repeat engagement in activity days/residential or through the CYPC) are more likely to report

having a support network, feeling more confident and feeling more able to cope with cleft related challenges.

To achieve the BLF indicators/outcome targets in year 2 onwards the project needs to:

- Increase the number of opportunities for engagement and for repeat engagement so that children and young people develop peer networks, build confidence and learn coping mechanisms.
- Ensure that activities deliver opportunities for children and young people to learn mechanisms for dealing with cleft.

### **Creating opportunities for children and young people to come together**

CLAPA levered in additional funding (from Children in Need) to deliver engagement activities for children and young people. This funding has been critical to the achievement of outcomes.

- Without this funding, the project's capacity to create opportunities to bring young people together – and to achieve the target outcomes - is limited.

CLAPA has been successful in raising further funding from Children in Need deliver a series of events aimed at engaging children and young people. The funding period (May 2018-May 2020) means that CLAPA RC Project will be able to continue to deliver activities for children and young people for the period of the Big Lottery project.

### **Increasing numbers of young people involved versus depth of engagement**

The evaluation evidence shows that building support networks takes time - children and young people need opportunities to come together with others with cleft to build their own confidence, and to feel comfortable before they will share experiences etc.

A challenge for the future will be to balance the requirement to deliver 'repeat opportunities' for children and young people who have started to engage with CLAPA with the need to create opportunities for new young people to join the networks.

### **Ensuring that activities are focused on delivery of outcomes**

While activity days have been popular with children and young people and have allowed young people to make friends, realise they are not the only one with cleft and built confidence, the events do not in themselves contribute toward the outcome (Indicator 2: increased knowledge of mechanisms for coping with cleft-related challenges)

CLAPA has changed the focus and content of the activity days in year 2. The days will still provide fun and opportunities to get to know other young people with cleft, but will also include learning about coping with cleft.

## **Progress toward outcomes for adults**

### **Outcome: Adults affected by cleft lip and/or palate (cleft) are more able to cope with cleft-related challenges**

The target for reaching adults in year 1 was very low (6). The key activity which delivers outcomes for adults is the Peer Support Service.



6 people were matched with a peer supporter through this service. While feedback shows that the service was helpful for those who gained support, we have not carried out further evaluation due to the very small number of users.

### **Learning and issues for the future**

CLAPA recognises that it has fewer services aimed at adults affected by cleft and has been working to address that gap.

CLAPA has been successful in leveraging additional funding to employ an Adult Services Coordinator to develop services for adults affected by cleft. The new post holder came into post in March 2018. The post holder will research the needs of adults with cleft and work with Regional Coordinators to develop new services to address these needs in each of the regions.

## Progress toward outcomes for parents and guardians

The table summarises the progress against each indicator

Indicators	Year 1 targets	
Parents/guardians report having access to a local support network	58	<p><b>Happy Faces Groups</b></p> <ul style="list-style-type: none"> <li>• 28 responses</li> <li>• <b>100%</b> had met other people they could talk to about cleft-related issues</li> <li>• <b>96</b> had access to support from others in the group (4% reported no change/neutral)</li> </ul> <p><b>Parents/guardians involved in local networks</b></p> <ul style="list-style-type: none"> <li>• 71 responses</li> <li>• 97% of parents felt part of a community</li> <li>• 97% of parents felt that they had a support network</li> </ul>
Parents/guardians report increased confidence in supporting their child with cleft-related challenges	50	<p><b>Happy Faces Groups</b></p> <ul style="list-style-type: none"> <li>• 28 responses</li> <li>• 94% in total felt more confident in supporting their own child with cleft-related issues</li> </ul> <p><b>Parents/guardians involved in local networks</b></p> <ul style="list-style-type: none"> <li>• 71 responses</li> <li>• 94% had more confidence in supporting their child with cleft related challenges</li> </ul>
Parents/guardians report being more able to cope with cleft-related challenges	79	<p><b>Happy Faces Groups</b></p> <ul style="list-style-type: none"> <li>• 28 responses</li> <li>• 96% felt better able to cope with cleft-related challenges</li> </ul> <p><b>Parents/guardians involved in local networks</b></p> <ul style="list-style-type: none"> <li>• 71 responses</li> <li>• 94% felt better able to cope with cleft related challenges</li> </ul>

## Learning and issues for the future

The project has been very successful both in its reach and impact on parents and guardians. The level of attendances at Family Days and local events highlights the reach of the project.

- There have been a total of 850 attendances at local events throughout the first year of the project. (Includes parents, guardians, children with cleft, siblings, and other family members)

The evaluation shows that parents/guardians have very variable levels of engagement but that their involvement in local activities and through social media makes them feel less isolated and part of a larger community of people affected by cleft.

Parents value the opportunities to learn from other parents, and over 90% said they were more able to cope as a result of their involvement in CLAPA. Parents and guardians also demonstrate a high level of interest in 'giving back' – many of the comments reflected their satisfaction in being able share their experience to help others in the network, and many parents are active volunteers.

### **The capacity of the project to engage more parents and guardians**

Although social media has proved popular and effective as a mechanism to share information and support, the provision of local events and activities is critical to engaging parents and families.

However, the capacity to deliver more events across the regions is limited by:

- the scale of the regions (the RCs cover huge geographic regions) and
- the local infrastructure/number of local volunteers who are prepared to deliver activities

The on-going challenge for RCs is to balance the need grow and sustain the volunteer base with the need to directly deliver activities in areas where there are few volunteers and gaps in activities to engage parents at the local level.

## Issues impacting on the delivery of outcomes

### **Staff vacancy**

Activity in the East Region has been hampered by a 6-month staff vacancy. This is a significant gap in a 3-year funded project and has affected activity levels in the East Region. The post has now been filled (as of February 2018).

### **Engaging volunteers**

Volunteers are central to the delivery of activities to people affected by cleft. The number of events and types of events that can be delivered in each region depend on the number of volunteers and the interest of those volunteers.

Although the qualitative feedback from people who have benefited from CLAPA services demonstrates that many are people keen too 'give something back' to the cleft community, the capacity of the project to create more volunteer roles and support more

volunteers is limited. While the review of the branch structure will create a range of different roles aimed at increasing opportunities for volunteers, the original target for engaging volunteers appears to be unrealistic, and should be revised downwards to reflect the capacity of the RCs to support volunteers.

The Regional Coordinators Project has also struggled to engage volunteers in formal training days, even although the training strategy (of regional development days rather than national training events) was developed after consultation with 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.

### **Response to the challenges**

- **Review of the branch structure**

The review of the branch structure was, in part, a response to the challenge of engaging volunteers. Regional Coordinators found that many volunteers were interested in supporting other people with cleft, but were less interested in engaging in the formal governance structures associated with branches. The new 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 which provides 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.

- **Training volunteers**

In response to the challenges of getting people to attend training, (and recognition of the reality that it is difficult for volunteers to give up their weekends to attend training) the RC Project is continuing to review and develop its volunteer training strategy. The project is currently exploring the development of on-line training and one-to-one training to make training more accessible to volunteers.

### **Engaging cleft teams**

Partnership working with Cleft Teams is important to the success of the project.

- Cleft Teams are in contact with everyone in the treatment pathway, so are critical source of referral to CLAPA ensuring that more people affected by cleft are aware of the services available.
- There is involvement of Cleft Teams in the advisory group for the project, and
- In most areas, Cleft teams work alongside CLAPA (e.g. in one area, Cleft Nurse Specialists attend Happy Faces Groups, providing parents with greater access to information and advice on cleft related issues).

However, engagement with local cleft teams is variable across the three Regions. RCs continue to try broker links with cleft teams but this is not always successful at the local level (and staff workloads in the cleft teams and changes in staff mean that it can be difficult to sustain relationships with cleft teams).

### **Refining the monitoring and evaluation systems**

During the first year of the project, CLAPA has been refining the logic model for the Regional Coordinators Project (to demonstrate the causal link between the activities and the outcomes it delivers), and developing its monitoring and evaluation systems to provide better measurement of outcomes and to generate better learning from the delivery of the project.

CLAPA has learned that it needs to improve its monitoring system to track individual attendances at events.

- This will allow CLAPA to better identify the number of people who have engaged rather than the number of attendances.
- This will help to demonstrate parents and young people's journey and help to better understand which types of activities are important in delivering outcomes.

There have also been challenges in gathering evaluation data at events so CLAPA has explored the use of short electronic surveys to collect feedback on impact. To date, this has been successful (71 parents responded to survey) and CLAPA will continue to explore on-line surveys to collect evaluation data in future.