

The contribution of a charitable organisation to regional cleft lip and palate services in England and Scotland

Abstract

Background: From diagnosis through to adulthood, a cleft lip and/or palate (CL/P) poses a number of challenges for those affected. Alongside the care provided by clinical teams, complementary information and support is offered by charitable organisations. In 2011, the Cleft Lip and Palate Association (CLAPA) received funding to implement a new regional service across England and Scotland, with the aim of increasing support at a local level. (*Team*) at (*university*) were commissioned to conduct an independent evaluation of the service over seven years.

Methods: A pragmatic, mixed-methods approach was utilised to assess the impact of the service from the perspective of charity volunteers; children, young people, and adults with CL/P; caregivers; and clinicians. Feedback forms were distributed to stakeholders at a variety of events, and qualitative feedback was collected via focus groups and an online survey.

Results: The majority of participants indicated they had gained access to a local support network, felt more able to cope with CL/P-related challenges, and felt more confident in themselves. Qualitative investigation provided further support for these findings, and highlighted additional benefits of the regional service for clinical teams.

Conclusions: The evaluation provides encouraging evidence toward the contribution of a relatively small charitable organisation in the context of cleft care. The importance of a pragmatic approach to community-based evaluation and the benefits of collaborative working between researchers and the charitable sector were also highlighted.

Key words: cleft lip and palate, charity, peer support, evaluation, quality of life

27 Introduction

28 From the point of diagnosis through to adulthood, a cleft of the lip and/or the palate (CL/P) poses a number of
29 challenges for those affected and their families (Nelson et al., 2012a; Stock & Feragen, 2016). For most
30 caregivers, the ‘diagnostic event’ is an emotionally demanding experience, and families often express a number
31 of concerns for the child’s future (Nelson et al., 2012a). Complex multidisciplinary care continues as the child
32 grows, and can form an underlying stressor in the family’s lives (Nelson et al., 2012b). CL/P and its treatment
33 can also present difficulties for the affected individual in many domains of life, including several areas of
34 psychological and social functioning (Lockhart, 2003; Collett & Speltz, 2007; Stock & Feragen, 2016).
35 Previous research has suggested that if left unmanaged, these experiences may evoke anxiety, social
36 withdrawal, low mood, and poor self-esteem (Rumsey & Harcourt, 2004), in addition to longer-term impacts on
37 education and health (Wehby & Cassell, 2010; Wehby et al., 2015). While the treatment pathway for those
38 born with CL/P typically concludes around the age of 16-18 years, research has indicated a number of unmet
39 needs in the adult population (Stock et al., 2015). Access to appropriate information and support across the
40 lifespan is therefore vital to facilitate psychosocial adjustment among families, children, young people and
41 adults affected by CL/P.

42 In the United Kingdom (UK), the delivery of cleft services is divided between 16 multidisciplinary teams.
43 These teams provide specialist support and clinical care to all individuals born with CL/P and their families.
44 Complementary information and support is also provided by the UK’s only dedicated charity, the Cleft Lip and
45 Palate Association (CLAPA). The charity was set up in 1979 as a partnership between parents and health
46 professionals, and constitutes a network of volunteer-led branches and groups, with a national office based in
47 London. CLAPA endeavours to improve the quality of life of all those born with CL/P and their families by
48 offering a wide range of support services. This includes the provision of specialist feeding equipment;
49 producing and distributing accurate information; training volunteers to provide peer support; offering
50 confidence-building activities for children and young people; representing the needs of people affected by CL/P
51 to other stakeholders; encouraging and supporting research; raising awareness of CL/P amongst the general
52 public; and fundraising in the community (*see* www.clapa.com).

In 2010, CLAPA conducted a national survey as part of their strategic review, open to all CL/P stakeholders across the UK (Preston, 2010). The key finding to emerge from this survey was the need for support to be provided at a local level. While a low degree of local support was already being delivered by CLAPA's network of volunteer-led regional branches, significant limitations and gaps in this service had been observed. In addition, the number of active branches across the UK was gradually decreasing, due to insufficient numbers of volunteers and a lack of resources. In response, CLAPA obtained funding to pilot the position of a dedicated Regional Coordinator (RC) in the East of England for one year between 2011 and 2012. The role of the RC was to act as a local point of contact for anyone affected by CL/P; to train and support local volunteers; to organise and support local events, branches and groups; to liaise with cleft teams and the local community; and to contribute to national policies and strategies, in order to increase support services in that region. Following a successful pilot project, CLAPA was granted further funding to employ three RCs in the East, Central, and South East regions of England. One new RC was introduced each year using a staggered approach between 2012 and 2016. During this time, new volunteering protocols were implemented, local branches were restructured, and new services and activities were established. Funding was later obtained to expand the RC Project into Scotland over the course of three years (2015-2018).

The seven-year project (2011-2018) was independently evaluated by (*centre*) at (*university*) against four key outcomes:

- 1) Volunteers report gaining transferable new skills, feeling more confident in their role, and being more able to support others affected by CL/P;
- 2) Children and young people born with CL/P report having more friends they can talk to about CL/P, being more able to cope with CL/P, and feeling more confident about themselves;
- 3) Adults born with CL/P report having access to a local support network, being more able to cope with CL/P, and feeling more confident about themselves;
- 4) Caregivers of child(ren) born with CL/P report having access to a local support network, feeling more able to cope with CL/P, and being more confident in supporting their child.

This paper presents the findings from quantitative and qualitative investigations, conducted as part of this evaluation. In addition to describing the key achievements and lessons derived from the project, the aim of the paper is to highlight the potential contribution of charitable organisations to overall cleft care.

Method

Design

The evaluation employed a pragmatic approach, utilising mixed methods to assess the impact of the project over the seven year period. At the beginning of the project, focus groups ($n = 8$) were conducted in each region with caregivers ($n = 19$), young people with CL/P ($n = 16$), adults with CL/P ($n = 4$), and health professionals working in the field ($n = 6$) to identify key areas of need and to collect feedback on the proposed plans for the project. Next, age-appropriate feedback forms were designed to directly capture the key indicators of the project. Feedback forms included a series of brief positively or negatively worded statements, such as “As a result of attending this event, I feel more able to cope with cleft-related challenges” (adults with CL/P); “As a result of attending this event, I have increased confidence in supporting my child who was born with a cleft” (caregivers); and “After going to this event, I have made friends who I can talk to about having a cleft” (children and young people). Participants were asked to indicate the extent to which they agreed with each statement on a 5-point Likert scale, ranging from “strongly agree” to “strongly disagree”. Three open-ended questions were also included to highlight what participants enjoyed about the event and what they felt could be improved, in order to guide the organisation of future events. Volunteers were also invited to complete a feedback form immediately following a training session, and at regular intervals during their service. Questions for volunteers included: “As a result of this training, I feel that I have gained useful and transferrable new skills” (training session); and “I feel confident in my role as a volunteer” (follow-up). Toward the end of the project, a further four focus groups (one in each region) and two qualitative online surveys (one in England, one in Scotland) were conducted to gather participants’ views on the overall success of the project. The questions posed by the online surveys were different to those included in the regular feedback forms, and focused on the extent to which beneficiaries had experienced a change to services in their region over the course of the entire project. Questions included: “If any, what do you consider to be the benefits of having a Regional Coordinator

05 in your area?” “How important would you say it is that the Regional Coordinator remains in post, and why?”

06 “Have your expectations of the Regional Coordinators Project been met so far, and why/why not?”

07 *Procedure*

08 Ethical approval for all aspects of the project was granted by the Faculty Research Ethics Committee at
09 (*university*). In all cases, participants provided written informed consent for their anonymised data to be used
10 for research and service development purposes. In the case of young people under the age of 16 years, parental
11 consent was also required.

12 Feedback forms

13 To allow for data capture in real-time, anyone attending a regional CLAPA event and/or a volunteer training
14 event were invited to complete a feedback form on the day. Events included (but were not limited to) family
15 days out, fundraising events, summer and Christmas parties, peer support groups, and residential weekends.
16 Following each event, completed feedback forms were transported to (*centre*) for electronic data entry and
17 subsequent analysis.

18 Focus groups

19 Potential participants were approached via advertisements published on websites and social media platforms
20 associated with the charity, and were encouraged to contact the researchers. Participants received information
21 about the purpose and agenda of the focus group, in addition to information regarding ethical issues (such as
22 data confidentiality and their right to withdraw) in advance, and were given several opportunities to ask any
23 questions. All participants provided written informed consent prior to the focus group commencing. Focus
24 groups were carried out by (*authors*), all of whom are trained in qualitative methods. On average, the groups
25 lasted one hour and 56 minutes. Focus groups were audio recorded with participants' permission, and later
26 transcribed verbatim. Inductive thematic analysis (*see* Braun & Clarke, 2006) was carried out on the data by
27 (*authors*) in order to identify key themes, and findings were then discussed among the team as a whole to
28 ensure full agreement.

29 Online survey

The online survey platform Qualtrics was used to collect the data (www.qualtrics.com). Again, potential participants were approached via advertisements published on websites and social media platforms associated with the charity. As described above, participants viewed information about the project and were required to indicate their informed consent prior to completing the online survey. (Authors) synthesised qualitative data according to the impact on the various stakeholder groups, and findings were discussed among the team as a whole to ensure full agreement.

Participants

Since the purpose of the initial focus groups was to gain feedback from beneficiaries to guide the design of the project, the data gathered from these have not been included in this paper. Feedback forms were collected from 522 caregivers, 247 children and young people with CL/P, 44 adults with CL/P, and 111 volunteers. Fourteen caregivers, ten young people with CL/P, seven adults with CL/P, and four health professionals participated in the focus groups, and a further 82 stakeholders completed the online qualitative survey.

Results

In total, 924 feedback forms were collected for the evaluation. The percentage of each group who met the key outcomes (“agree” or “strongly agree”) was calculated. On average, 79 percent (range: 71-89) of caregivers, 80 percent (range: 71-85) of children and young people with CL/P, 94 percent (range: 87-95) of adults with CL/P, and 85 percent (range: 77-89) of volunteers reported meeting the key outcomes of the evaluation. These findings are presented in **Table 1**. A further subset of participants responded neutrally (‘no difference’), which was most often attributed to their involvement with CLAPA prior to the implementation of the new regional services (e.g. “I was part of a CLAPA group anyway so I already felt supported”). In the case of those who responded negatively (“disagree”), a fair proportion reported a discrepancy between the purpose of the event and the feedback item (e.g. “I am an active volunteer already, so although I don’t feel I learned new skills from this event, I did refresh my existing skills”). None of the 924 participants responded using the “strongly disagree” option. No differences in the findings were observed between the two countries, and no event achieved better outcomes than others. However, participants from Scotland often commented that they had to

travel a great distance to attend events due to the size of the region, and found it more difficult to connect with the service as a result. In addition, and throughout the course of the evaluation in Scotland, a strategic surgical review of the NHS clinical service in Scotland was underway (see www.nsd.scot.nhs.uk), which ultimately resulted in all surgical care moving to a single site in Glasgow. A large proportion of the RC's time was therefore spent acting as a conduit between different stakeholders, which may have affected the focus of the project.

Analysis of the data derived from the four concluding focus groups and the online survey were organised into four key themes: impact on volunteering activity; impact on children, young people and adults; impact on caregivers and families; and impact on cleft teams. Each theme is outlined below and illustrated with exemplar quotes. Participants have been given pseudonyms to preserve their anonymity.

Impact on volunteering activity

New volunteering standards and training protocols were implemented as part of the project. Participants commented on the benefits of refining their role and of systematising volunteering processes.

"[The protocols] put everything into a structure and the training is invaluable for skill-building... I have an identification badge and it all feels a lot more professional" - mother, involved with CLAPA for seven years.

Participants also discussed how overall volunteering activity had increased as a result of the project.

"The events are much better attended, much better organised, and more focused... We feel that we're making a real difference" - mother, involved with CLAPA for 15 years.

As a consequence of the project, volunteers reported feeling more supported in their role.

"We certainly feel empowered to do more, and that's very much because of the fact that as volunteers we are now much better supported" - father, involved with CLAPA for 21 years.

Participants also believed that communication between volunteers had greatly improved.

"There's a real feeling of cooperation...much more interaction with other volunteers and more cohesion" - mother, involved with CLAPA for seven years.

80 Finally, participants believed that the project had provided volunteers with greater opportunities to raise
81 awareness of CL/P, both within the cleft community and among the general public.

82 *“Awareness of cleft has definitely improved... I’ve seen an increase in phone calls from schools and other*
83 *groups in the wider community, now that they are more aware of where to turn for support”* - cleft team
84 member, involved with CLAPA for 10 years.

85 Impact on children, young people and adults

86 As a result of the increase in regional activity that the project created, participants believed that children and
87 young people affected by CL/P had become less isolated.

88 *“To see the children actually talk to each other about going through the same speech problems or school*
89 *issues...I don’t think you can measure how invaluable that is”* - cleft team member, involved with CLAPA for
90 18 months.

91 Participants also commented on the increase in confidence they had observed among children and young people
92 with CL/P throughout the duration of the project.

93 *“CLAPA’s regional services have given young people a voice... They are taking ownership; it’s empowering*
94 *them and giving them confidence... That is something I didn’t have growing up”* - adult born with CL/P,
95 involved with CLAPA for two years.

96 Participants reported on the development of new activities for young people with CL/P, which had not been
97 previously available.

98 *“The Residential Weekends are so important for children with clefts. I have made so many friends and the*
99 *support I’ve had is amazing! I would definitely go again”* – young person with CL/P, involved with CLAPA
00 for 14 months.

01 Participants also spoke of the importance of the project in reaching out to adults affected by CL/P.

02 *“Prior to this I had no awareness that something which could help adults like me existed... It has been hugely*
03 *beneficial for me to have a network of others affected by cleft... I can also share knowledge/coping mechanisms*

04 *and give back to those who are not as confident as myself” - adult affected by CL/P, involved with CLAPA for*
05 *18 months.*

06 Impact on caregivers and families

07 Caregivers described the project as having provided an additional source of reliable information, as well as peer
08 support and advice.

09 *“My wife and I did used to feel very isolated and alone... To know there’s someone reliable nearby that you*
10 *can go to is so valuable... As a parent, the regional services have provided support, an outlet for concerns and*
11 *a community to turn to when things get difficult” - father, involved with CLAPA for 16 months.*

12 As a result of the service, caregivers described having more confidence in supporting their child(ren).

13 *“Other people have been through the same things and it makes you realise you are doing OK as a parent... I*
14 *have a renewed belief that we can support [our son] through whatever comes next” – mother, involved with*
15 *CLAPA for three years.*

16 Having received support as part of the project, participants described how they had been inspired to become
17 volunteers themselves.

18 *“The effect on us as parents and as a family has been huge... I have become far more involved with the charity*
19 *now, so I can give something back to the community and keep things going” - mother, involved with CLAPA*
20 *for five years.*

21 Impact on cleft teams

22 Participating health professionals believed the relationship between the regional cleft teams and CLAPA had
23 grown stronger, and reported that the project had a positive impact on their patients.

24 *“The relationship is much more organised, and the charity has a better profile within the hospital and across*
25 *the region as a whole. The project has added value to the patient journey, given patients and parents better*
26 *access to local support, and facilitated the organisation of joint events and fundraisers which would otherwise*
27 *not have happened” - cleft team member, involved with CLAPA for 10 years.*

Participants also felt that contact between health professionals and families had increased over the course of the project.

“We have more involvement with the health professionals now, and they seem a lot more accessible... You get to hear what’s happening first hand, and you can see how it’s all evolving... It feels like we’re all on one team”
- father, involved with CLAPA for 14 years.

Participants were also of the opinion that CLAPA’s regional service offers support to patients and families which is complementary to that offered by the cleft teams.

“As much as we would like to offer all the support that the families need at the hospital, CLAPA can offer something different that doesn’t come from anywhere else... They can offer flexible support, which is not encumbered by as many barriers as [the hospital], in terms of working hours, location of events, and being able to actively go to those in need, rather than waiting for them to come to you” - cleft team member, involved with CLAPA for 18 months.

Discussion

This paper has outlined the findings from an independent mixed methods evaluation designed to assess the contribution of a charitable organisation to CL/P services in England and Scotland. Feedback collected from various events over the seven year period indicates that between 71 and 95 percent of volunteers, children and young people with CL/P, adults with CL/P, and caregivers met the key outcomes of the project. The lowest percentage achieved across all groups was related to the indicator “more able to cope with CL/P-related challenges”, which may suggest that although the regional service impacted upon coping indirectly, improving coping skills was not a key focus of individual events.

Qualitative data further alluded to a number of achievements of the project. In the case of volunteers, the standardisation of volunteering protocols provided structure and brought a sense of legitimacy to the role. Volunteers reported feeling empowered and well supported, and felt their contribution to the organisation was valued. Volunteers also described an increase in communication, improved cohesion and more cooperation between volunteers based in different parts of the two countries. As a result, volunteers reported a clear

54 increase in volunteering activity and awareness-raising within the community, and an overall sense of
55 satisfaction with their role. As well as having a significant impact on beneficiaries and the community as a
56 whole, research in the voluntary sector has demonstrated a positive effect of volunteering on the physical and
57 mental wellbeing of the volunteers themselves (Casiday, 2015). Given the positive feedback received, it
58 appears that volunteers may be benefitting from the regional service, as well as contributing to it.

59 Participants also identified a number of impacts of the project upon children and young people with CL/P. In
60 particular, the project created a variety of opportunities for children and young people to engage in activities
61 with one another and to share their experiences of CL/P. Although the evidence base examining the support
62 needs of children and young people with CL/P is relatively small (Sharif et al., 2012), research has identified a
63 number of potential challenges, including a feeling of 'being different' from their peers (Berger and Dalton,
64 2009; Havstam et al., 2011). Getting to know others with similar experiences may therefore act as a buffer
65 against negative social encounters (Feragen et al, 2010), reduce feelings of isolation, and increase children and
66 young people's confidence.

67 According to the feedback collected, a notably high percentage of adults recorded positive responses to the key
68 outcomes of the evaluation, demonstrating the potential value of support services for this group in particular.
69 Several CL/P studies have identified a number of unmet needs in adulthood, including access to information
70 and further treatment, genetic counselling, and psychological support (Ramstad et al., 1995; Yttri et al., 2011;
71 Stock et al., 2015). Routine CL/P treatment in the UK typically concludes around the age of 16-18 years, and
72 how to best reach this population in the years that follow remains an ongoing challenge for cleft teams and
73 charitable organisations (Stock et al., 2015).

74 Caregivers who contributed data to the evaluation described CLAPA to be a source of reliable information, and
75 to provide a variety of opportunities for caregivers to meet other families and to share advice. This was
76 particularly powerful if other families were slightly further ahead in the treatment pathway, as has been
77 described in previous literature (Nelson et al., 2012b). Previous research has demonstrated the importance of
78 caregivers feeling well supported and informed at all stages of the treatment pathway (Nelson et al., 2012a), and
79 it appears that charitable organisations could help to achieve this imperative. Caregivers who participated in

80 this evaluation also reported feeling part of a community, and were inspired to ‘give back’ to this community
81 by becoming volunteers themselves. **This suggests that if supported and monitored carefully, a self-sustaining**
82 **network of volunteers can be created.**

83 Finally, participants agreed that regional activities had improved the relationship between CLAPA and the cleft
84 teams, and had made clinicians more accessible to patients and families. As a result, caregivers could see how
85 their input was directly influencing service development and research initiatives. In addition, clinicians felt that
86 CLAPA’s profile within the region had improved, and that there had been a mutually beneficial increase in
87 knowledge exchange between the charity and the cleft teams. Several papers have described the importance of
88 interdisciplinary working among cleft team members (e.g. Fox and Stone, 2013; Scott et al., 2014), and it is
89 reasoned that this concept should also be extended to collaborative working alongside charitable organisations
90 (*also see* Clarke, 1999).

91 Collectively, these data suggest that the various patient groups consider the regional services offered by
92 CLAPA to be a valuable resource for themselves and others. The potential benefits of support services offered
93 in conjunction with clinical care have also been demonstrated among patients and families affected by other
94 craniofacial conditions (Tiemens et al., 2006; Heike et al., 2010; Bogart et al., 2016), as well as mental ill
95 health, disability, and chronic illness (e.g. Mahlke et al., 2014; Lauckner and Hutchinson, 2016; Tully et al.,
96 2017). Collaborative working between clinical teams and charitable organisations is therefore key to ensure the
97 delivery of a holistic service, giving patients and families access to a variety of support options throughout the
98 treatment pathway.

99 Another important priority for the craniofacial field is the evaluation of interventions to promote positive
00 psychological adjustment among patients and families, in order to build a stronger evidence base (Norman et
01 al., 2015; Stock et al., 2017). Yet, a key challenge in conducting an evaluation within the community is the
02 need to balance rigour with pragmatism. Evaluation methods chosen on the basis of their credentials as robust
03 approaches may not always work well in practice. Outcomes, processes, and methods of measurement must all
04 be negotiated. However, huge benefits for both sides are evident if this is well-matched. In the case of the
05 current project, a pack of standardised measures could not be utilised due to the real-world nature of data

06 collection, and the researchers had limited control over how and when the data were collected. An estimation
07 of the number of feedback forms returned relative to the number of event attendees could not be made due to
08 missing information. Nonetheless, the current evaluation has provided encouraging evidence of the benefits of
09 the project, and has supported the acquisition of further funding for the continuation and expansion of
10 CLAPA's services. In return, the project has provided an opportunity for the findings of the evaluation to be
11 implemented directly and immediately into practice.

12 **Conclusions**

13 This paper has highlighted the key achievements and contributions of a charitable organisation to regional CL/P
14 services. Benefits for volunteers, children and young people with CL/P, adults with CL/P, caregivers, and cleft
15 teams were observed. In addition, the evaluation has yielded benefits for the charity itself in relation to ongoing
16 service development, funding acquisition, and the roll-out of evidence-based practice. The findings of this
17 paper demonstrate the potential benefits of cooperative working between researchers and the charitable sector,
18 and advocate a comparable approach to service delivery for related organisations in other parts of the world.

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