



**The Sick Kids
Friends Foundation**
Helping sick kids & their families since 1992



**The Hugh
Fraser
Foundation**

**Tay Charitable
Trust**

CLAPA Regional Coordinators Project: Scotland

Evaluation Interim Report

Focus group study in Scotland (Inverness)

May 2016

Contributors:

Mr Matthew Ridley (Research Associate, Centre for Appearance Research)

Dr Nicola M. Stock (Research Fellow, Centre for Appearance Research)

Ms Gillian McCarthy (Senior Scotland Regional Coordinator, Cleft Lip and Palate Association)

Ms Melanie Skinner (Scotland Support Officer, Cleft Lip and Palate Association)

Ms Claire Cunniffe (Deputy Chief Executive, Cleft Lip and Palate Association)

Professor Nichola Rumsey (Co-Director, Centre for Appearance Research)



This report was produced by the Centre for Appearance Research, University of the West of England in Bristol on behalf of the Cleft Lip and Palate Association.

Contact for further information:

Mr Matthew Ridley (Research Associate, Centre for Appearance Research)
Matthew.Ridley@uwe.ac.uk

Dr Nicola Stock (Research Fellow, Centre for Appearance Research)
Nicola2.Stock@uwe.ac.uk

Ms Gillian McCarthy (Senior Scotland Regional Coordinator, CLAPA)
Gillian.McCarthy@clapa.com

Ms Claire Cunniffe (Director of Development, CLAPA)
Claire.Cunniffe@clapa.com

Report Contents

Introduction.....	4
Method.....	5
Key findings	6
Theme 1 – Location barriers.....	6
Theme 2 – Support provision.....	8
Report Summary.....	9
Recommendations.....	9
References.....	10
Lay summary.....	11

Introduction

Background and project rationale

Cleft lip and/or palate (CL/P or 'cleft') is the most common congenital craniofacial condition, affecting approximately one in every 700 live births per year in the UK. The cleft and its treatment can pose a number of challenges for those affected and their families, and having access to appropriate support should it be needed is a vital factor in facilitating psychosocial adjustment.

A national survey conducted by the Cleft Lip and Palate Association (CLAPA) in 2010 found that families and individuals affected by CL/P wanted more support in their local area. Subsequently, CLAPA responded to this by developing the Regional Coordinators Project, with the aim of introducing and improving localised services for individuals and families affected by CL/P. This project is in its fourth year in England and as a result of its success, the project has now been extended to Scotland. Although the first financial year began in June 2015, the SRC did not begin in post until September 2015.

Funding for this project has been provided by the Big Lottery Fund, The Robertson Trust, The Sick Kids Friends Foundation, Glasgow Children's Hospital Charity, the Scottish Government Social Care Directorate, the Hugh Fraser Foundation and the Tay Charitable Trust. The Centre for Appearance Research (CAR), based at the University of the West of England in Bristol, has been commissioned to conduct an independent evaluation of the project.

Project Outcomes

The CLAPA Scotland Regional Coordinators Project has four key outcomes:

Outcome 1: People affected by cleft are better able to cope with their condition

Outcome 2: People affected by cleft have increased confidence

Outcome 3: People affected by cleft feel less isolated

Outcome 4: Parents of children with a cleft are better able to support their children with cleft-related challenges

This report

This report details the findings obtained from a small focus group held in Scotland (Inverness) during Year One of the project. The aim of the focus group was to ascertain what support is currently lacking and what improvements CLAPA can make to the support they offer in Scotland. Normally, at least one other focus group would be carried out in the region as part of CAR's evaluation during the first year. However, in preparation for the submission of relevant Scotland funding applications, CLAPA had already carried out two focus groups (with CAR's input) prior to the commencement of the project, and therefore only one further focus group study was deemed necessary in order to collect a suitable amount of data. This focus group was conducted in Inverness; an especially isolated area of Scotland. Details of the original two focus groups may be obtained from CLAPA upon request.

Review of cleft surgical services in Scotland

It is important to note that during the course of the project's first year, an official review of cleft surgical services in Scotland by the National Services Division (NSD) has been ongoing. As a result of this review, a proposal has been made for a significant change in these services. Specifically, surgical activity will be reduced from two sites (Glasgow and Edinburgh) to one site (Glasgow) in the near future. A public consultation phase is currently coming to a close before these recommendations are finalised. This review is part of the NHS in Scotland, and is separate to CLAPA. Nonetheless, the SRC has been actively involved in this review since her appointment, spending a considerable amount of time ensuring the views of affected families and individuals are communicated to the NSD.

Method

Study design

A qualitative approach was employed to ensure the collection of rich data pertaining to people's experiences of the support available in Scotland, and of support which may be needed/lacking. One small focus group was held in Inverness on Saturday 27th February 2016.

Recruitment and participant characteristics

The focus group study was reviewed and approved by the Department of Health and Social Sciences' Ethics committee at the University of the West of England.

All participants were over the age of 18 years and were either a parent of a child with cleft ($n = 2$) or an adult with cleft ($n = 1$). All participants identified as White British. Participants were recruited through advertisement by social media (e.g. CLAPA Facebook – regional and main), via the CLAPA website and through email. The SRC also telephoned potential participants directly and contacted the cleft teams in the region.

Despite considerable initial interest, only three participants attended the focus group. All three had travelled from Skye (approximately 2.5 hours). Also present was the Senior Scotland Regional Coordinator to aid the organisation, and a representative from the CAR who facilitated the running of the focus group.

Participants were provided with a Participant Information Sheet in advance, which gave details of the focus group study, including why it was being conducted and what being a participant would involve, as well as information on the right to withdraw from the study. Written consent was obtained from each participant on the day, prior to the commencement of the focus group.

Data collection

The focus group was held face-to-face in Inverness. An open-ended, semi-structured focus group interview schedule was used. Topic areas included which services (generic and specialised) participants currently

access and their pros and cons; what services they feel are currently lacking in the region; and their past and potential future support needs.

The focus group lasted approximately 90 minutes and was audio recorded. The recording was transcribed verbatim the CAR researcher who facilitated the focus group.

Data analysis

The transcript was analysed using inductive Thematic Analysis (see Braun and Clarke, 2006), which allows for common themes in the data to be identified. A second representative from CAR also analysed the data to check for consistency.

Key findings

Data analysis identified two main themes: 1) Location barrier and 2) Support provision. Each theme is presented below and is accompanied by example of quotes taken directly from participants. Recommendations based on the data obtained are also provided.

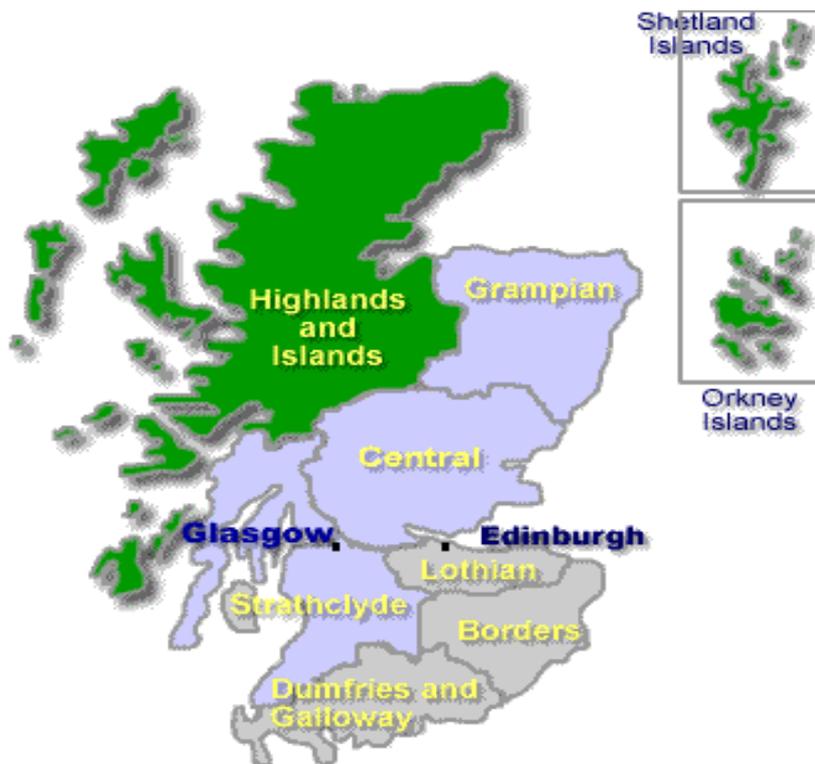
Theme 1: Location barrier

Participants consistently referred to location as a barrier to accessing appropriate levels of support. This was seen as particularly relevant to those living in the 'rest of Scotland' (for example, in the Highlands and Islands) when compared to the Central Belt (see Figures 1 and 2 below). Despite this, the participants communicated their enthusiasm for local support to be implemented. Indeed, this is evident in the distance all three participants travelled to be part of the focus group.

Figure 1. Map of the Central Belt



Figure 2. Map of the Highlands and Islands



When considering the perceived inconsistency in levels of support across Scotland, the adult with CL/P stated:

“From my experiences I’d like to see something set up in the Highlands and Islands area... I was just lucky I was born in the Central Belt and not in the Highlands”.

In addition, both of the parents of a child with CL/P reported a lack of understanding of CL/P in their local area:

“They [non-specialist medical staff] don’t have the specialism (for cleft) or the numbers at [the local hospital]”.

Nevertheless, all of the participants conveyed that the cleft community is motivated to accessing support regardless of location barriers, and that there is an acceptance of the need to travel long distances occasionally:

(Parent) “We know we’re not going to get 1:1 support, even in the Central Belt...living in the Highlands you accept that...folk might think it’s a long way from Skye to Edinburgh but you just get used to [travelling]”.

Underlying this location discrepancy within Scotland was the general feeling that CLAPA is an English organisation. Consequently, participants believed that CLAPA is not well known in Scotland, and that as an organisation CLAPA lacks an identity in Scotland.

(Adult) "Just recently I accessed the CLAPA website...I didn't even know [CLAPA] existed. I'd never even heard of it and I've had this (cleft) for 41 years. I'm told CLAPA started 36 years ago but even then I was never put in touch with CLAPA".

Theme 2: Support provision

The second main theme that emerged from the focus group concerns support provision, both in terms of what services are available and what participants would like to see implemented.

Both parents described their experiences with the cleft teams, the hospital and the NHS in general as a positive example of support:

"The NHS have been fantastic...we've had one on one with the cleft teams...the cleft nurses, and that's been our main source of support".

The adult participant described both positive and negative elements of the support they had gained in the past from local NHS hospitals and from specialist NHS cleft teams. They described the teenage years as a particularly challenging period when they would have benefitted from appropriate support:

"From my experience the teenage years is when I could have done with more support...it would have helped me if there was a group of teenagers with cleft that were brought together".

The parents also agreed that peer support would be beneficial:

"Locally we don't have anything...we are looking to speak to other parents with the same issues we might have".

This led to a discussion around ways in which such local (e.g. in and around Skye) support networks could be developed. Together, the group reached a potential solution, which would involve developing links with other groups/charities/societies:

(Adult) "The autism societies seem to have a very good network up there (Highlands), from nothing".

(Parent) "Possibly join the autism and cleft parents together because we might get a few more people and parents".

(Adult) "Possibly other long term conditions [e.g. diabetes, heart conditions, cystic fibrosis] as well because a lot of the teenagers are going through the same thing of being different".

(Parent) "If you're a parent of a child with a difference I don't think it matters what that difference is".

Report summary

Throughout the focus group it was evident that local support was necessary, particularly in areas located outside of the Central Belt. This is something a SRC could provide, and thus this role could be seen as a valuable addition in Scotland.

Location was identified as a key barrier to obtaining support. The fact that the focus group participants travelled from Skye is telling; first, that accessing support is currently more difficult in some areas than in others, and second, that people affected by CL/P may be motivated to access support even when travel over long distances is required.

Underlying this location barrier was the more general sense that CLAPA lacks an identity in Scotland, and likely more so in the areas outside of the Central Belt. There is a large task ahead to enhance the profile of CLAPA across the whole of Scotland, as well as to develop creative strategies for developing local support networks and activities.

The idea of developing links with other groups/charities/societies emerged during discussions between the participants and the SRC during the focus group. In particular, participants stressed that, at least initially, support need not be restricted to those affected by CL/P, but that the needs of individuals and families affected by any health condition or 'difference' were likely to overlap. Engaging with existing organisations has the potential to bring families and individuals together, with the additional advantage of learning from organisations who are already established in the region.

Another area for the SRC to target moving forward is enhancing CLAPA's relationship with the NHS cleft teams, and with local hospitals and other community resources. For example, raising awareness of CL/P and of the services which CLAPA offer, and promoting the patient voice in service delivery have been raised in previous reports (visit the CLAPA website for further information: <https://www.clapa.com/about-us/goals-strategies/regional-coordinator-project>).

Finally, it emerged from the focus group that what one individual/family might need is likely to differ from that of another. Therefore, CLAPA and the Scotland SRC need to employ a flexible and individualised approach wherever possible.

Overall, an SRC could fulfil the role of a gatekeeper and facilitator to developing local support networks and activities.

Recommendations

- There is a need to increase the number and range of events and activities across Scotland for all age groups, and particularly in more remote areas, such as the Highlands and Islands.
- Ways of promoting CLAPA across Scotland need to be considered in order to increase CLAPA's reach and uptake of services, and to enhance the organisation's identity in the region.
- Engaging further with the cleft teams and the local hospitals may be highly beneficial, particularly given that these were identified as a positive example of support. Subsequently, CLAPA could act as an additional and complimentary line of support for affected individuals and families.
- Similarly, a useful exercise may be to engage with and learn from other existing groups/charities/societies in Scotland, to enhance CLAPA's presence and influence.
- There is a need to adopt an individualised, flexible approach to support, particularly as service provision and access varies greatly across Scotland. What one individual/family requires is likely to differ from another, and is likely to change over time.

References

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101

Preston, R. (2011) *CLAPA 2010 survey results*. Cleft Lip and Palate Association, London.

Lay Summary – Scotland focus group study (Inverness)

Overview of the Regional Coordinators Project

The Cleft Lip and Palate Association (CLAPA) Regional Coordinators Project aims to increase the amount of local support offered to those born with a cleft lip and/or palate (CL/P) and their families. This project is in its fourth year in England and as a result of its success, the project has now been extended to Scotland.

Funding for this project has been provided by the Big Lottery Fund, The Robertson Trust, The Sick Kids Friends Foundation, Glasgow Children's Hospital Charity, the Scottish Government Social Care Directorate, the Hugh Fraser Foundation and the Tay Charitable Trust. The Centre for Appearance Research (CAR), based at the University of the West of England in Bristol, has been commissioned to conduct an independent evaluation of the project.

Project Outcomes

The CLAPA Regional Coordinators Project in Scotland has four key outcomes:

Outcome 1: People affected by cleft are better able to cope with their condition

Outcome 2: People affected by cleft have increased confidence

Outcome 3: People affected by cleft feel less isolated

Outcome 4: Parents of children with a cleft are better able to support their children with cleft-related challenges

Focus group study in Scotland (Inverness)

A small focus group was held in Inverness to ascertain what support is currently lacking and what improvements CLAPA may be able to make to its services in Scotland. Two parents of children born with CL/P and one adult born with CL/P took part. Details of two other focus groups held in Scotland previously may be obtained from CLAPA upon request.

The topics raised in the focus group were condensed into two main themes:

1. **Location barriers** – location is a significant barrier to accessing support in Scotland, particularly outside of the Central Belt. Currently, local support is rare and CLAPA lacks an identity in Scotland.
2. **Support provision** – a significant increase in the number and range of events and activities across Scotland for all age groups is required. A flexible approach is needed; what one family needs is likely to be different from another. Engaging with NHS cleft teams and other organisations may be highly beneficial.

Thank you to everyone who contributed. To find out more about the Regional Coordinators Project in Scotland and how you can contribute, please visit www.clapa.com or contact Nicola Stock (CAR): Nicola2.Stock@uwe.ac.uk, Matthew Ridley (CAR): Matthew.Ridley@uwe.ac.uk, Claire Cunniffe (CLAPA): Claire.Cunniffe@clapa.com or Gillian McCarthy (CLAPA): Gillian.McCarthy@clapa.com.

