

# CLAPA Adult Services Project

## Information for UK Cleft Teams

### About the Project

This is a three year project funded by the VTCT Foundation to research and understand the experiences, challenges and unmet needs of adults in the UK who were born with a cleft lip and/or palate (cleft). Following this, in the 2nd and 3rd years of the project, **the Adult Services Coordinator (ASC) and CLAPA team will work to develop and implement services designed to address current unmet need and roll these out across the UK.** At the conclusion of the three years, should the project prove successful, funding would be sought to continue the delivery of the services.

### About the Adult Services Coordinator

The ASC is a new role which has been established to undertake this project and the position is funded for three years. Our ASC, **Kenny Ardouin**, is a new addition to the CLAPA team. Kenny joins us from Christchurch, New Zealand to take on this role having previously worked in New Zealand as a Speech and Language Therapist for a number of years and, prior to that, as the CEO of Cleft New Zealand. Kenny also has lived experience of growing up with cleft lip and palate. The ASC will be the main point of contact for this project.



### What will it involve?

In the first year, **the project will be largely focussed on researching and identifying the needs of adults who were born with cleft**, and this will be led by the ASC. This will include a literature review of existing research. Additionally, we will review internal data we have on our database, social media and evaluation from our Regional Coordinators (RCs) & Engagement Officers (EOs) regarding the common issues that adults with a cleft report to us. This will help form the basis for developing a comprehensive survey seeking the thoughts and experiences of adults with a cleft.

Our CLAPA **Adults Voices Council (AVC) (or a subgroup thereof) and Patient Participation Groups** will provide feedback during the development of the survey to ensure it gives us a robust picture of the experiences of adults who were born with a cleft. It is anticipated that **this survey will be ready in summer 2018.** Additionally, in the summer, the ASC, in conjunction with the CLAPA RCs & EOs, will endeavour to deliver an event in each of the CLAPA regions. These events will encourage people to complete the survey, raise awareness across the UK that cleft affects adults too, and provide a safe space and a platform for people to share experiences.

The qualitative information gathered in this way will be a valuable supplement to the information captured by the survey and also can be **used to help identify gaps in adult services.** It is hoped that adults with no connection to CLAPA or Cleft Teams may discover these days and wish to come along. Following the formal business of the day, it is hoped that a social activity can be run for adults with cleft in the evening as a means of them getting to know one another and reduce feelings of isolation.

Following the completion of the survey and the roadshow, analysis on the data will begin to identify the common themes affecting adults and suggested services. This will be collated and a preliminary discussion held on the outcomes at a **CLAPA Adults Mini Conference in November**, with a full report estimated for completion in February 2019. Following this, recommendations will be made on how to proceed for the second year where new adult services can be trialled and delivered.

## What do we hope to achieve?

In the first year (March 2018 – February 2019), we hope to get a good overview of the experiences of adults with a cleft as well as any facilitators and barriers with regard to their participation in their living fulfilled lives, as well as with regard to their engagement with further treatment.

Following this, we would hope to be able to deliver services tailored to address the needs that our research has highlighted.



## What can Cleft Teams do to help?

There are a few different things you can do to help us with the project in its first year.

- ✓ Talk to your adult patients about the project and upcoming survey, and, where appropriate, encourage them to take part.
- ✓ Help us with the PR campaign. We want to be able to capture the experiences of adults with a cleft who may not know about CLAPA services (some may have even dropped out of the health system decades ago), and so we will need everybody's help to spread the message far and wide. You can help by talking with people, displaying posters and other materials relating to the project which we will provide from time to time, sharing posts relating to the project on social media, features in newsletters etc.
- ✓ Nominate a key contact person in your cleft team who can receive information about the project and share it with the rest of the team. Please have your key contact get in touch with the Adult Services Coordinator so that we ensure you receive all the upcoming information about the project.
- ✓ Let us know about cleft services available for adults in your area – where do adults go to receive treatment for your cleft centre (i.e. are they treated at the same or a different location as children), and how do they get seen again by the team as an adult?
- ✓ Attend our roadshow event in your area if possible. It would be fantastic to have you come along to our roadshow event in your region – given that there may well be adults with a cleft attending who are not currently under the care of a Cleft Team, having your expertise in helping people back into the health system (both logistical and moral support) will be invaluable. Additionally, if you can help us in any way with these days – for example, by offering a venue, please do let us know!

## Where can I get more information, get in touch and share ideas?

If you would like more information or to share your ideas, please do get in touch with the CLAPA Adult Services Coordinator:



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