

Notes from Focus Group meeting Saturday 24th April 2010

Session 1

During this session we explored –

- **What prompted people to join the group?**

It was felt that adults had been under represented by CLAPA in the past and that adults had specific needs/issues which needed to be discussed and addressed. Some thought that CLAPA had been targeting families with young children and adults had been sidelined.

Some people had only recently become aware of CLAPA and had had very little psychological support and were interested in finding out what was now available.

It was welcomed as 'live' interaction, where people would meet face-to-face and not over the internet via forums and chat room's. It was thought that although we had provided a forum for adults to meet up (conferences) the emphasis had been on presentations with not enough time allocation for discussion.

- **The purpose and responsibilities of the group.**

- A unique opportunity to talk to people who are willing to talk about being an adult with a cleft.
- A focus group should generate ideas.
- To look at issues specific to adults and look at ways of making information more accessible.
- To look at how we raise awareness of CLAPA and NHS services available to adults.
- Provide adults with a 'voice' and empower them to make decisions and inform us of issues that we should be addressing.

- **The key issues we should be addressing?**

Reaching the 'older generation' who may not be computer literate as it was felt that we were providing a lot of information online and discussed how to disseminate information specifically for adults.

Confusion around referrals by GP's as they were often unaware of the specialist cleft teams and referred to the wrong clinicians or in the case of dentist's some were not referring at all and recommending costly treatment that should be provided free by the cleft teams. As many of the cleft teams are based at children's hospitals many adults were unaware that they could also get treatment via these centres.

There was a need to highlight access to the secondary issues such as psychological support, orthodontists, dentures, genetic issues as many of these services were not available prior to the CSAG review in 1998. There is not enough information available on the CLAPA website or even the internet in general about issues relating to adult treatment. We discussed the provision of forums specifically for adults and many were unaware that we did in fact have a forum on our website and that there was also the Face Forward forum for adults. However, those adults that had used them found that if they wanted to talk about the negative aspects of have a cleft they were treated in a dismissive way and it was as if every issue had to have a happy, resolved outcome which is not always the case. Our Facebook page is very active but posts there do not tend to deal with serious issues and was thought not to be anonymous enough. It was akin to sharing your problems in a frivolous way with the whole world. However, there is the option to open a discussion topic and send private messages if you want.

Because of new treatment techniques it was thought that health professional could be quite dismissive of previous operating procedures which at the time actually improved the quality of life for many adults and that it felt quite insulting to them and that health professionals should be made aware of this.

We discussed coping strategies. How do you deal with children asking questions such as "Why do you speak differently?" It was felt that the psychology services offered to children could be extended to adults and highlighted the services of Changing Faces. It was pointed out that in general it was more of a sounding different problem rather than a looking different problem. It was thought that providing biographies on the CLAPA website would be useful to adults. It was also suggested that CLAPA could lobby on behalf of adults for better provision of psychological support but the group thought that in the light of the current financial downturn this was not seen as a realistic option. It was thought that self promotion with individuals pushing their cleft team would be more effective. It was suggested that perhaps

CLAPA could keep records, by region, when they became aware of adults having difficulties accessing the service and then using this information to lobby for better service provision.

We discussed regional CLAPA services/branches and how they were mainly providing for young families and not for adults. Some of those present would like to meet with other adults in their regions, not just to discuss treatment options but also for social/emotional interaction. We discussed 's plans to regionalise our service and this would be an opportunity to set up a network of adult group meetings. One of the options raised was for CLAPA to set up a 'Buddy' system for individuals who wanted to contact another person in their region.

Research was brought up and we spoke about current projects being carried out by the Centre for Appearance research -

<http://hls.uwe.ac.uk/research/about-car.aspx>

who do a lot of research on appearance issues. We are often approached by researchers asking for participants so we want to build up an awareness of research amongst our members and how research operates so that if you do take part in a project you can do so actively and that you would be the ones suggesting the research that you feel is necessary or relevant and being involved from the start. We also discussed the funding for the Gene Bank looking at factors that affect or cause cleft lip & palate, and also a study of clinical excellence looking at interventions and treatments. We are looking to involve our members in this research and are looking at training to enable them to have the skills to contribute as a user representative of the service. We are planning a dedicated Research page on the CLAPA website to highlight research that is currently being undertaken and also publish finished projects.

We talked about extending our celebrity patrons and those mentioned were:

- John Henshaw - Actor
- Andy Parsons - Comedian
- Rabbi Jonathan Romain
- Mick Palmer MP
- David Llewellyn – Opera singer

We talked about practical information that could be on our website such as career options and also careers that are prohibited by having a cleft. This also led to a discussion around voluntary community work in your local area to raise confidence.

Session 2

Notes from the workshop from the CLAPA Conference 2009 were handed out (see attached) and it was obvious that most of the suggestions from that day had been replicated in morning session.

The belief was that a focus group was good at generating ideas but not for putting things into action.

We discussed how or if the group would progress and what form it might take in the future. It was decided that in order to set an action plan the recommendations from the group would shape its own future.

There was the possibility that it would morph into an Adult Council or steering group of 10 or 12 people which held regional meetings (possibly 4 per year) or communicate via email, telephone conferencing or regular meetings in a forum or chat room. This group would be proactive in advising CLAPA of adult needs and setting a work agenda for CLAPA. It would look at current services available and advise accordingly. It was seen as a good mechanism for delivering the following three recurring themes though out the day:-

- Information dissemination – look at ways of reaching adults born with a cleft.
- A Forum – mechanism for people with clefts to communicate with other people
- Mentoring/Buddy scheme

Many of those attending the focus group would be very interested in committing to being a council member. It was thought that they would be a self-selecting group and that once set up it would monitor and approve applications from those wanting to become members.

We also had a discussion about other ways that adults could be come involved with CLAPA via the new volunteer program which includes training on how to give presentations locally, help put on activity, talking to the media to raise awareness of cleft lip & palate. There is information relating to this on the CLAPA website.

It was agreed that everyone who had attended felt that there was a need for change and that they all had individual agenda's but they all felt that they all wanted to be involved in some way. However, it was felt that it would be good to have a period of reflection to think about everything that had been discussed during the day.

Actions

- CLAPA to advertise the setting up of an Adult Council and seek applications from interested adults.
- CLAPA to put together a draft constitution and remit for the group.
- Once Council members are in place CLAPA would facilitate the first meeting.
- Extend the Adult page of the CLAPA website to include biographies/case studies.
- CLAPA to circulate notes of this meeting via email to all those who attended or showed an interest in the group and also contact details for all those who attended this meeting.
- CLAPA to present the findings of this group to the Adult workshop on Saturday 15th May 2010 in Nottingham.