

CLAPA Conference 15th May 2010

Adults Workshop

Following the morning presentation by Arthur Winn, CLAPA Trustee whose presentation explained the history of CLAPA services for adults and the progress made following the 2009 Conference in Birmingham, this group discussed the outcomes from the recent Focus Group held at CLAPA National office and its outcomes.

We focused mainly on the setting up of an Adult Council comprising of eight to twelve members and discussed the structure of the group and its aims. Everyone who attended agreed that the principal aims as laid out in the Focus group notes were relevant and that CLAPA should begin the recruitment process immediately.

We went on to discuss some of the issues raised by the focus group and the adults who attended discussed their experiences of treatment referral. As we had two people from overseas in the group (USA & Spain) it was interesting to hear from them how they access treatment in their respective countries. It was clear that the experiences of the group were vastly different especially as those from overseas as they did not have the benefit of the level of service provided by the UK specialist cleft teams and it was also evident that access to treatment in the UK is still not easy and there is a need to signpost routes to treatment centres more proactively.

Also attending the workshop was Martin Persson from Bristol Dental School who is project managing the CSAG II (Clinical Standards Advisory Group) review. He expressed the need for adult involvement in research projects and that adults had a responsibility to take an active role and have a 'voice' and that they had a unique experience of cleft services prior to the original CSAG review and would give his team a basis to evaluate how the adult service had, or had not, improved.

Dr Alison Williams and her assistant Dr Bhavin Soneji spoke to the group about their research project: *Issues to adults born with cleft lip & palate surrounding the arrangements and delivery of NHS cleft care.*

The aim of this study is to identify the outstanding issues that adult patients with cleft lip and/or palate have regarding the delivery of multidisciplinary cleft care. This information will be used to help the development of adult cleft services in the future. In order to get quality feedback they would like to undertake telephone interviews and any information gathered will remain anonymous.

Dr Elizabeth Barry also needs to recruit adults from East Anglia into her study programme: *A study into cognitive beliefs about the Self and the World in those born with a cleft lip*, which is focused on the Cleft Net East region.

Dr Barry is working on her MSc Psychology degree and is running the study in conjunction with Dr Anna Zeffert, Clinical Psychologist at Addenbrookes Hospital, Cambridge. She is piloting a programme to identify issues that may be significant to adults born with cleft lip and/or palate. If you are interested in taking part you can find more information, a link to the questionnaire and a consent form on our website www.clapa.com.

This workshop was facilitated by Sue Carroll, CLAPA Deputy Chief Executive