Young people with an intellectual disability and cleft lip/ palate

Amanda Bates, Tizard Centre, University of Kent, e-mail: ajb61@kent.ac.uk

Aim:
To find out and compare how young people with and without intellectual disabilities (ID) and a cleft feel about themselves and their cleft care.

Background:
Nearly half of those with a cleft have a learning or language disability (Ceponiene et al. 2000), but those affected have received little attention from researchers. Billaud-Feragen and Stock (2014) reported difficulties for children with additional conditions to a cleft. The specific presence of an ID and a cleft however has not yet been explored.

ID research suggests that behavioural problems might occur for those who have an additional condition to an ID. Is the presence of an ID a significant additional stressor for young people with clefts? Also, is one condition more difficult to cope with than another?

Method:
Qualitative study using semi-structured interviews with 15 young people aged 9-15, their parents (n=16) and, healthcare professionals (n=9). Interview guide topics included thoughts about appearance, social experiences and treatment experiences.

Emerging results are as follows:

- Having an ID as well as a cleft raises more challenges (particularly in accessing educational support)
- Some children made positive comments about their appearance, but bullying was also a concern
- Some children with an ID weren’t aware they looked different
- Positive relationships with the cleft team were reported
- Although not connected with the cleft team, some parents reported traumatic experiences with operations
- Health Professionals would welcome further training in ID and legislative issues
- Health Professionals gave examples of an individualized approach to care.

Conclusion:
It is important to consider the impact of an additional medical condition for people with IDs in order to plan appropriate support, training and care. Data analysis is still in progress and final themes and results will be made available in due course.