

Kent Academic Repository

Full text document (pdf)

Citation for published version

Bates, Amanda and Forrester-Jones, Rachel and McCarthy, Michelle (2018) The experiences of children and young people with a learning disability/need and a cleft lip and/or palate. In: Craniofacial Society of Great Britain & Ireland (CFSGBI) Annual Scientific Meeting, 18-20 April 2018, Birmingham, UK. (In press)

DOI

Link to record in KAR

<http://kar.kent.ac.uk/66653/>

Document Version

Author's Accepted Manuscript

Copyright & reuse

Content in the Kent Academic Repository is made available for research purposes. Unless otherwise stated all content is protected by copyright and in the absence of an open licence (eg Creative Commons), permissions for further reuse of content should be sought from the publisher, author or other copyright holder.

Versions of research

The version in the Kent Academic Repository may differ from the final published version.

Users are advised to check <http://kar.kent.ac.uk> for the status of the paper. **Users should always cite the published version of record.**

Enquiries

For any further enquiries regarding the licence status of this document, please contact:

researchsupport@kent.ac.uk

If you believe this document infringes copyright then please contact the KAR admin team with the take-down information provided at <http://kar.kent.ac.uk/contact.html>

The experiences of children and young people with a learning disability/need and a cleft lip and/or palate

Bates, A.J., Forrester-Jones, R. and McCarthy, M.

Background

International research suggests 7%-18% of those born with a cleft lip and/or palate (CL±P) also have a learning disability (LD). However, there is no known UK research about the qualitative experiences of living with both conditions, so support needs are unknown.

Methods

Fifteen semi-structured interviews were conducted with CYP with CL±P, ten of whom had LDs/learning needs. Interview topics included cleft clinic experiences/treatment, self-perceptions and social activities. Thematic Analysis was used to identify data patterns.

Findings

Three superordinate themes were found: self-image, resilience and struggles. A range of self-image perceptions were described ('normal', otherness and positive), with bullying victims having a poor self-image. Resilience was evident for CYP without LDs (e.g. quality friendships, control over treatment). There was an association between school type (mainstream/Special Educational Needs and Disability (SEND) schools) and positive/negative experiences. CYP without LDs and CYP with LDs in SEND schools had more positive experiences than CYP with LDs/needs in mainstream schools who frequently reported difficulties. Difficulties encompassed bullying (resulting in a desire for surgery), and treatment burden (e.g. fear of needles/anaesthetic).

Discussion

Having LDs/learning needs were strongly linked with struggles (bullying and treatment burden). However, mediating factors such as how far CYPs' needs and rights were met in hospital and school were pivotal. Further research into these environmental influences, with a view to better supporting CYP with CL±P and LDs/needs, is welcomed.