

## Letter to the Editor


**Cite this article:** Ooues G, Pope N, and Hudsmith LE (2020) Are healthcare professionals aware and trained in dealing with Adult Congenital Heart Disease patients with learning difficulties? A questionnaire-based study. *Cardiology in the Young* 30: 448–449. doi: [10.1017/S1047951119003214](https://doi.org/10.1017/S1047951119003214)

Received: 4 October 2019  
Accepted: 13 December 2019  
First published online: 13 January 2020

### Author for correspondence:

Dr Lucy Hudsmith, Department of Cardiology, Queen Elizabeth Hospital Birmingham, Birmingham B15 2TH, United Kingdom.  
Tel: 00441216272000;  
E-mail: [lucy.hudsmith@uhb.nhs.uk](mailto:lucy.hudsmith@uhb.nhs.uk)

# Are healthcare professionals aware and trained in dealing with Adult Congenital Heart Disease patients with learning difficulties? A questionnaire-based study

Georgina Ooues , Nichola Pope and Lucy E. Hudsmith

Department of Adult Congenital Cardiology, Queen Elizabeth Hospital Birmingham, Birmingham, UK

## Dear Editor-in-Chief

Children with CHD are at increased risk of cognitive and motor disabilities.<sup>1,2</sup> Those with complex CHD and, particularly, cyanotic lesions are at the highest risk for neurodevelopmental impairment.<sup>3,4</sup> With the increasing survival of patients with CHD into adulthood, consequently 10% of Adult CHD patients have some form of learning disability.<sup>5</sup> According to NHS England Congenital Heart Disease standards of care<sup>5</sup>, all patients should be seen and treated in an appropriate adult environment, ideally within a dedicated ward or outpatient space, taking into account any learning or physical disability. All healthcare professionals dealing with these patients must take part in ongoing education and training on working with adults with learning disability.

We sought to understand the awareness of our multi-disciplinary staff of the services available across our West Midlands Adult Congenital Heart Disease Network for our patients with learning disabilities.

Anonymous questionnaires were distributed to healthcare professionals working in all eight Outreach Centres and the Level 1 Adult Congenital Heart Disease Centre (University Hospital Birmingham). The questions included information on their current position, place of work, the frequency of their encounter with patients with learning disability, their previous training, and the awareness of inpatient and outpatient facilities available for these patients. Data were analysed only from the information filled by healthcare professionals in the returned questionnaires.

Seventy healthcare professionals (25% nurses, 39% doctors, 20% cardiac physiologists, and 16% healthcare assistants) completed the questionnaires. The majority of staff (n = 54, 46%) were working in the outpatient areas and were encountering patients with learning disabilities weekly (n = 28, 41%) or monthly (n = 32, 46%). Only 11% of staff (n = 8) had received formal training in dealing with these patients, while a further 31% (n = 22) felt that they had received some informal training during their career. The formal training consisted of the General Medical Council online interactive learning module on learning disabilities. Only 56% of healthcare professionals (n = 39) were aware of their hospital's policy on learning disabilities; however, the majority were familiar with one of more of the facilities available in the outpatient (n = 48, 69%) and inpatient setting (n = 43, 61%) for these patients, such as provision to prioritise their appointment, resource boxes, sensory room, patient passport, and the role of Learning Disabilities Specialist Nurse. Nursing staff were more likely to have received some formal training in dealing with learning disabilities than doctors (61 versus 48%) and were more aware than doctors of the facilities available in the outpatient (89 versus 59%) and inpatient (67 versus 59%) setting for these patients.

To the best of our knowledge, this is the first study evaluating the awareness of medical and nursing staff of the services available to Adult CHD patients with learning disabilities. Overall, healthcare professionals have some knowledge of the facilities available and have received sporadic training. However, ongoing training and education is required to ensure appropriate and lifelong holistic management of all these patients throughout the network.

**Acknowledgements.** None.

**Financial Support.** This study received no specific grant from any funding agency, commercial or not-for-profit sectors.

**Conflicts of Interest.** None.

## References

1. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation* 2012; 126: 1143–1172.

2. Farr SL, Downing KF, Riehle-Colarusso T, et al. Functional limitations and educational needs among children and adolescents with heart disease. *Congenital Heart Disease* 2018; 13: 633–639.
3. Rollins CK, Newburger JW. Neurodevelopmental outcomes in congenital heart disease. *Circulation* 2014; 130: e124–e126.
4. Wray J, Sensky T. Congenital heart disease and cardiac surgery in childhood: effect on cognitive function and academic ability. *Heart* 2001; 85: 687–691.
5. NHS England. Adult Congenital Heart Disease (ACHD) Specification. NHS England, 2016. <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>