

Managing the transition from children's to adults' healthcare services



April 2020

Response by the National Deaf Children's Society Cymru

About Us

The National Deaf Children's Society is the national charity dedicated to creating a world without barriers for deaf children and young people.

We support deaf children and young people with all levels of hearing loss from mild to profound, including those with a unilateral loss (hearing loss in one ear) and temporary hearing loss.

Our Response

The National Deaf Children's Society Cymru believe it is essential that the needs and voices of D/deaf young people are acknowledged, understood and addressed during the transition from children to adult health services.

After carefully considering the consultation, we would like to offer the following feedback.

1) Transition and Handover Lead

3.1 Health Boards will be expected to identify a named Transition and Handover lead (Assistant Medical Director, Nurse Director or Director of Therapies) with accountability for ensuring implementation and quality of the transition and handover guidance across all primary, secondary, and tertiary healthcare services. In addition, the named Transition and Handover lead will be responsible for liaising with other statutory agencies to ensure that mechanisms are in place so that young people and their families with complex needs receive a co-ordinated transition experience.¹

It is essential that the assigned Transition and Handover lead for a deaf young adult possesses deaf awareness. The role of a Transition and Handover lead should be to facilitate and lead a young person's transition as part of the core team working around them. Many of the core team members will not have working knowledge of D/deafness. It is, therefore, essential that the Transition and Handover lead can fully advocate for the needs of the deaf young person- an approach that can only be undertaken if they themselves possess a strong knowledge of the

¹ Welsh Government, *Managing the transition from children's to adults' healthcare services*, n.p.n, Available at: https://gov.wales/sites/default/files/consultations/2020-01/consultation-document_1.pdf

needs and nuisances of D/deafness. We would welcome all Transition and Handover leads across all health boards receiving deaf awareness training. Providing deaf awareness training in this way is in line with action 5 in the NHS Wales *Framework of Action for Wales 2017-2020: Integrated Framework of care and support for people who are D/deaf or living with hearing loss*.² It is also in line with the Future Generation Commissioner's *The Art of the Possible* Simple Step number 32, which recommends that public services train frontline staff in deaf awareness.³

2) Feedback

3.2 Health boards should ensure that feedback from the young person is captured so that the voice of the young person is heard and at the centre of care. There should be a continuity of care across all services.⁴

The National Deaf Children's Society Cymru fully support measures to ensure the individual voice of the young person is at the centre of their own care. D/deaf young people may communicate using a variety of methods including British Sign Language (BSL), Sign Supported English (SSE), oral and/or written language. For some D/deaf young people, particularly those who are BSL first language users, their use of English may be limited. BSL is a recognised language with its own grammar and linguistic rules. This may mean they have difficulty in accurately conveying their feedback in written form. Sufficient steps should be undertaken to ensure that all D/deaf young people can have their feedback heard and captured. It is important, that the guidelines set out within the NHS Wales *All Wales Standards for Accessible Communication and Information for People with Sensory Loss*⁵ are met in this regard.

3) Technology

During the transition period, it is essential that young people are given full support to manage their own assistive technologies. For many young people, parents will have played a large role in organising the updating and repair of assistive technologies. Young people transitioning into adult care must be given the knowledge and expertise to manage this themselves.

4) Availability of BSL interpreters and communication support.

D/deaf young people who are BSL users must be made aware of their right to have BSL interpreters/communication support at their medical appointments. Too often, parents are relied on to act as 'interpreters'. This should not be happening, no matter the age of the D/deaf person. All D/deaf persons, irrespective of their age, have the legal right to be provided with a BSL interpreter at their appointments if required and requested. As part of the transitioning

² NHS Wales, 2017, *Framework of Action for Wales, 2017-2020, Integrated Framework of Care and Support for People who are D/deaf or Living with Hearing Loss*. Available at: <https://gov.wales/sites/default/files/publications/2019-03/integrated-framework-of-care-and-support-for-people-who-are-d-deaf-or-living-with-hearing-loss.pdf>

³ See <https://futuregenerations.wales/aop/offer-deaf-awareness-training-and-british-sign-language-bsl-training-for-your-staff-particularly-for-those-on-the-front-line/>.

⁴ Welsh Government, *Managing the transition from children's to adults' healthcare services*, n.p.n, Available at: https://gov.wales/sites/default/files/consultations/2020-01/consultation-document_1.pdf

⁵ NHS Wales, 2013, *All Wales Standards for Accessible Communication and Information for People with Sensory Loss*. Available at <http://www.cardiffandvaleuhb.wales.nhs.uk/sitesplus/documents/1143/Sensory%20Loss%20Standards.pdf>

process, it is essential that their right to BSL interpreters at all appointments is reiterated and communicated to D/deaf young people.

It is also imperative that the departments who will be working with the deaf young person moving forward are aware of and have appropriately recorded details of the young person's communication needs.

In addition, the National Deaf Children's Society Cymru would highlight the importance of ensuring that advocacy support provided to the young person is able to meet their communication needs. We would also recommend that there is a section to outline a young person's communication needs in the example plan at Appendix 3.

5) My Life, My Health Resources

Co-produced with D/deaf young people, the National Deaf Children's Society has produced a range of materials to improve access to healthcare for D/deaf young people. Young people and professionals may find these resources useful during the transition period. We are happy to share print and digital copies of these with any health care professionals. You can access them online or contact us to receive print copies. Download digital copies here:

<https://www.ndcs.org.uk/documents-and-resources/my-life-my-health-all-the-resources-in-one-pack/>

6) Multi-agency working

Moving on into adulthood can be a challenging time for many – particularly for those who have additional learning needs (ALN) or disabilities. It is worth noting the role that health can play in working with other agencies to secure a smooth transition process for these young people. In particular, health staff may be asked to contribute to a young person's Individual Development Plan under the Additional Learning Needs and Education Tribunal Wales Act. There might be particular considerations at transitions stage for these plans and we would recommend that the health board DECLO, as the lead for collaboration with education, is mindful of this.

In addition, social care support for deaf young people can be particularly valuable during this life stage. Health professionals working with young people should be aware of the types of support that social care professionals may be able to provide to a young person and of how a referral can be made. As with the Individual Development Plan, health professionals might also be asked for information to input into such a social care assessment.

The Transition and Handover Lead might also play a key role in securing effective multi-agency collaboration. A Transition and Handover Lead who often works with deaf young people would benefit from connecting with the local CHSWG (Children's Hearing Services Working Group). These are multi-agency groups which meet to discuss local services for deaf children and young people.

More information

Thank you for the opportunity to respond. For further information please contact us at campaigns.wales@ndcs.org.uk