

Professionals working in health settings will be well aware of the value and importance of ensuring access to information to and promoting participation with young people.

This document sets out the relevant legislation and guidance in this area and is intended to support you in developing the case for action to ensure that deaf and other disabled young people receive information in a way that is accessible and that they are fully involved in discussions about their health.

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Equality legislation

In England, Scotland and Wales, the Equality Act 2010 sets out the public sector equality duty¹ which applies to professionals working in health. In particular, this requires public bodies to take steps:

- to have due regard to the need to minimise or remove disadvantages;
- to take steps to meet the different needs of disabled people and other people with different protected characteristics;
- encourage participation in activities by those whose participation is disproportionately low.

In Northern Ireland, the Disability Discrimination Act 1995 also requires public bodies to prevent discrimination against disabled people. The Northern Ireland Act also requires public bodies to have due regard to the need to promote equality of opportunity between persons with a disability and those without.

UN Conventions

A number of UN Conventions set out expectations that deaf and other disabled people have full access to health services.

For example, article 23 of the UN Convention on the Rights of the Child² states that every disabled child has the right to a full life and to active participation in the community whilst article 24 states that every child has the right to the best possible health and health services. In addition, article 12 stresses the importance of ensuring children can express their views and participate in decisions.

Article 25 of the UN Convention on the Rights of Persons with Disabilities³ states that disabled people should have access to the “same range, quality and standard” as health care and programmes as provided to other people. Article 7 stresses that “*all necessary measures*” must be taken to ensure disabled children can express their views and are given “*disability and age-appropriate assistance to realise that right.*” In addition, article 26 sets out the rights of disabled people to be independent and be fully included in society. This includes supporting participation and inclusion.

¹ <http://www.equalityhumanrights.com/advice-and-guidance/public-sector-equality-duty/>

² <http://www.crae.org.uk/childrens-rights-the-law/laws-protecting-childrens-rights/un-convention-on-the-rights-of-the-child/>

³ <http://www.crae.org.uk/childrens-rights-the-law/laws-protecting-childrens-rights/un-convention-on-the-rights-of-persons-with-disabilities/>

England

A policy of 'no decision about me, without me' has been enshrined in legislation and guidance in a number of different ways by the Department for Health.

- The **NHS constitution**⁴ contains a pledge to offer people *“easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices.”*
- The **Health and Social Care Act 2012**⁵ sets out new duties on health bodies to *“reduce inequalities between patients with respect to the accessibility of health services.”*
- The **NHS information strategy** (as set out in *The power of information*⁶) notes that *“Professionals need excellent communication skills for sharing information and for communicating with us in ways that the person receiving care can understand. This includes thinking about language and interpretation support and ensuring that all communications are in formats that each of us – as the individual recipient of the care – can understand”* and also highlights the need for more systematic recording of particularly information and support needs and preferences.
- The **You're welcome – quality criteria for young people friendly health services**⁷ highlights that appropriate health care means ensuring that services for young people are *“easily accessible by people with any form of physical disability or sensory impairment”* and expects that *“the service will provide information for people with physical disabilities or sensory impairments in an appropriate format.”*

Ensuring access to information and promoting participation will also help health bodies to demonstrate that Joint Strategic Needs Assessments have been drawn up with involvement from the whole community and effectively the needs of everyone.

Scotland

- The *Patients' Rights Act* was passed by the Scottish Parliament in 2011 and became law in April 2012. It aims to improve patients' experiences of using health services and to support them to become more involved in their health and health care. It gives all patients the right that the health care they receive should consider their needs, consider what would be of optimum benefit to them and encourage them to take part in decisions about their health and wellbeing. These rights are set out in a *Charter of patients' rights and responsibilities*⁸.
- A *national initiative* by Health Improvement Scotland known as *Better Together*⁹ was launched last year to focus on feeding the experiences of the public back into the design and improvement of NHS services. The initiative collects patient experiences through surveys and publishes the findings in Patient Opinion Service Evaluation Reports.

Wales

- **Together for Health**¹⁰ 2012 states *“The Welsh Government and NHS will provide better information on health and health care services. More will be done to help people understand health issues and manage their own care, including those who may need special support.”* The subsequent **Together for Health: Public Information Delivery Plan**¹¹ said *“The information the Welsh Government and the NHS provide should be carefully presented to help you make*

⁴ <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf>

⁵ <http://www.legislation.gov.uk/ukpga/2012/7>

⁶ <https://www.gov.uk/government/publications/giving-people-control-of-the-health-and-care-information-they-need>

⁷ <https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>

⁸ <http://www.hris.org.uk/patient-information/information-about-health-rights/charter/>

⁹ http://www.healthcareimprovementscotland.org/programmes/patient_experience/better_together.aspx

¹⁰ <http://wales.gov.uk/topics/health/publications/health/reports/together/?lang=en>

¹¹ <http://wales.gov.uk/topics/health/publications/health/strategies/plan/?lang=en>

decisions that matter to you and to understand what is happening in relation to your own health and to health care more generally.”

- **Consent in health care information for children and young people aged under 18 in Wales.** A leaflet¹² has been produced by the Welsh Government and outlines children and young people’s rights to be involved in decisions about their health, health care or treatment.
- In 2012, the Welsh Government, the NHS Committee for Equalities and Human Rights, Healthcare Inspectorate Wales (HIW), Action on Hearing Loss Cymru and RNIB Cymru, produced a report on **Accessible Healthcare for People with Sensory Loss in Wales**¹³. This report made a number of recommendations, including a recommendation that *“all healthcare organisations should have an Accessible Information Policy outlining how the communication needs of all patients are to be met including the needs of people with sensory loss.”*

Northern Ireland

- The Children’s Strategy (2006)¹⁴ established a number of pledges that government made to young people. These included supporting children and involving young people in decision-making. The strategy establishes an “outcomes framework” that sets out how government will measure how successful they have been in implementing the strategy. In addition, the Health and Social Care Board are currently reviewing the provision of interpreting services across Northern Ireland, including sign language and interpreting.

¹² <http://wales.gov.uk/topics/health/publications/health/guidance/consent/?lang=en>

¹³ <http://bit.ly/15PzFlc>

¹⁴ <http://www.ofmdfmi.gov.uk/index/equality/children-young-people/children-and-young-people-strategy.htm>