

Matthew Tester
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Department of Health and Social Services, Welsh Government
Cathays Park
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Dear Matthew,

Green Paper: Our Health, Our Health Service

The National Deaf Children's Society (NDCS) Cymru is the national charity dedicated to creating a world without barriers for deaf children and young people. We support and represent the interests of deaf children and young people from birth through to independence. In referring to "deaf" we refer to all levels of hearing loss, including mild, moderate, severe, profound and temporary hearing loss.

Part 1: Quality First and Foremost

Whilst we have considered all areas of the Green Paper we feel that our most valuable contribution relates to chapters 1- 6, which focus on quality.

Promoting Health and Wellbeing

Whilst we recognise and value the concept of prudent healthcare, it is important to acknowledge some of the particular barriers faced by deaf children and young people in accessing health services and health information.

The All Wales Standards on Accessible Communication for People with Sensory Loss were launched by the Welsh Government in December 2013. Research by Action on Hearing Loss Cymru, RNIB Cymru and Sense Cymru, earlier in 2015 indicated that 4 out of 5 respondents requiring communication support were not asked about this.¹ This is partly because health care settings are not aware of the requirements outlined in the Standards and partly because deaf people are not aware that the standards exist and that they confer certain rights.

90% of deaf children have hearing parents and often assumptions are made that parents will talk for their children in many circumstances. One example would be during GP appointments. Deaf young people, like every other young

person, will reach a stage where they will want and need to visit the GP independently. Deaf young people face significant barriers when reaching this stage, including lack of deaf awareness in surgeries and lack of knowledge about accessing communication support.

In 2014 the NDCS Youth Advisory Board launched a resource to support deaf children and young people at this important stage in their lives, "My life, my health".ⁱⁱ We were very encouraged by the support shown by the Health Minister, Mark Drakeford AM, and we are pleased to report that every GP surgery in Wales has received a copy of the leaflet which outlines what health professionals can do to support deaf young people.

This initiative is an example of how third sector organisations can have an impact. However, we believe that this responsibility should be shared across public services with a greater obligation placed on the NHS to proactively ensure that their systems and communication mechanisms are appropriate and easily accessible for all. This includes ensuring that those working within the NHS are deaf aware and sufficiently knowledgeable of the rights of a deaf child or young person to appropriate communication support.

It is worth noting at this stage that there are particular challenges for Welsh speaking deaf children and young people in accessing communication support which need to be addressed.

Continuously engaging with citizens

NDCS Cymru Wales welcomes consideration in the Green Paper of the need to engage with citizens regarding the development and delivery of services.

We acknowledge the potential benefits of Patient Participation groups and welcome their inclusion in the GP contract for 2014 – 2015.

Provision through the Social Services and Well Being Act for citizens' panels is also positive with the potential to utilise such groups at primary care cluster level.

Patient expert groups for LHBs and clear links to CHCs are also beneficial opportunities for citizen engagement.

We would support Welsh Government's suggestion to consider establishing, on a statutory basis, the requirement for health boards and NHS trusts to constitute permanent engagement mechanisms such as patient panels or participation groups. Although we would caution that such an approach would need to be proportionate and avoid duplication ensuring that such groups are empowered to undertake meaningful work.

In terms of engagement it is extremely important to ensure that any panels are made fully accessible for, and consult proactively with, deaf children and young people. There are particular barriers faced by deaf children and young people within the health service and we would strongly advocate that a deaf child or young person, or the parent or family member of a deaf child or young person, be included on these panels.

To that end, it is particularly important that a range of communication methods are used and appropriately promoted by patient panels and participation groups so as to ensure that deaf children and young people have sufficient opportunities to put their views forward.

In terms of written materials the following key points should be adopted to ensure that they are as accessible as possible:

- Information presented visually with use of images, animation and/or colour
- Broken down into chunks, using boxed out text, sub-headings, bullet points and bold text

- Uses simple language and avoids complex words, jargon or idioms
- Using short sentences

Further advice on making information accessible to deaf young people can be found online at: <http://www.ndcs.org.uk/document.rm?id=9325>

We would advocate that throughout the health service a variety of engagement methods are used to suit the diversity of communication methods used in communities in Wales.

If we can be of any further assistance during the consultation process please do not hesitate to get in touch.

Yours sincerely

Kate Cabbage
Policy and Campaigns Officer

ⁱ <http://www.actiononhearingloss.org.uk/news-and-events/wales/news/dignity-of-deaf-people-still-not-respected-by-the-health-service-in-wales.aspx>

ⁱⁱ <http://youngpeople.ndcsbuzz.org.uk/mylifemyhealth>