# NHS England consultation: Making health and social care information accessible

## A response by the National Deaf Children’s Society

## November 2014

### Consultation questions

1. **Do you agree with the vision for the standard?** The vision is explained in section 3 of the Consultation Document.

☐ Yes
☐ No
☐ Not sure
☐ Prefer not to say

2. **Do you agree with what the standard will do?** This is explained in section 4 of the Consultation Document and in the Specification.

☐ Yes
☐ No
☐ Not sure
☐ Prefer not to say

3. **Do you agree with what the standard includes?** This is sometimes called the scope. What the standard includes and who will have to follow it is explained in sections 5 and 6 of the Consultation Document and the scope forms section 8 of the Specification.

☐ The scope is about right
☐ The scope is too small
☐ The scope is too big
☐ The scope is missing something
☐ The scope includes something it should not
☐ Prefer not to say

4. **If you believe that the scope is too small or includes something that it should not, please explain here**.

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5. **If you believe the scope is too big or does not include something which it should, please explain here.**

We believe there needs to be a specific recognition that the information needs of disabled children and young people will be different from those of disabled adults.

In relation to deaf children and young people, although deafness is not a learning disability, some deaf children and young people may have low levels of literacy and/or low levels of confidence in engaging with health and social care professionals. We support the drive to making information accessible through, for example, the provision of communication support. However, for deaf children and young people, we strongly believe that for information to be accessible, special and separate consideration needs to be given to how it is given and presented.

Many deaf young people have raised concerns with us about information not being engaging or matched to their needs, as found in the National Deaf Children's Society My life, my health: deaf young people's experiences of health services report, available online at: http://youngpeople.ndcsbuzz.org.uk/downloads/download.php?f=downloads/assets/JR0419_MLMH_report_2014_WEB.pdf

We believe that a new field should be added so that it is possible to record that a disabled person has information needs relating to being a young person. The definition of "Young-person friendly" could include:

- 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

Other potentially helpful resources include:

- Guide to Producing Health Information for Children & Young People by the Patient Information Forum: http://www.pifonline.org.uk/products-page/product-category/guide-to-producing-health-information-for-children-and-young-people-3/

'Easy read' version of resources may go some way to addressing the above needs. However, most deaf children do not identify as having learning difficulties and would not normally look to use ‘easy-read’ versions as an alternative.

6. **What do you think about the steps of the standard / the Requirements set out for health and social care organisations and IT suppliers?** The steps of the standard are explained in section 7 of the Consultation Document and the Requirements are detailed in the Specification.

☐ The steps / Requirements are about right
☐ The steps / Requirements are too small
☐ The steps / Requirements are too big
☐ The steps / Requirements are missing something
☐ The steps / Requirements include something they should not
☐ The steps / Requirements are wrong in some way
☐ Prefer not to say

7. **If you think that the steps / Requirements are too big or include something which they should not, please explain here**.

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8. **If you believe that the steps / Requirements are too small or do not include something which they should, please explain here**.

Again, we believe it would be helpful if the standard encouraged health professionals to have specific regard for the needs of deaf children and young people.

For example, when information is delivered, as well as providing extra time, we also believe that health professionals should also be asked to check and confirm the young person’s understanding of what they have been told. It would also be helpful to highlight as well that young people should be spoken to directly, unless there are good reasons why not.

It would be helpful if resources accompanying the standard provide examples of best practice and also resources which could help professionals in training and their continuing professional development. For example, the Royal College of Paediatrics is currently developing a module on working with deaf young people.

This could be highlighted as a possible way of complying with the accessible information standard in relation to deaf young people.

Other possible resources include:

- Making information accessible to deaf young people: http://www.ndcs.org.uk/document.rm?id=9325
- The resources developed with deaf young people for the My Life, My Health campaign, available online at www.ndcsbuzz.org.uk/mylifemyhealth
- Glossary for British Sign Language interpreters: http://www.ndcs.org.uk/document.rm?id=8799

9. **If you believe one or more aspects of the steps / Requirements is / are wrong, please explain here**.

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10. **What do you think about the types of communication support and information formats we have included?** These are listed in section 8 of the consultation document and in the technical document which accompanies the Specification.

We suggest that the following be considered:

a) It would be helpful if under possible requirements for a communication professional, there is a recognition that there may be a need for an advocate with experience of working with disabled children and young people. This should be added to the list.
b) Under the possible requirements for communication support, it is recognised that some people may use a hearing aid, but not implantable hearing devices or radio aids / FM systems. These should be added to the list.
c) There doesn't seem be to a recognition that some services can be delivered online – for example, online British Sign Language interpreters or remote palantypists.

11. **Do you agree with quality considerations we have included?** This is outlined in section 10 of the Consultation Document and in the Specification for the standard (section 9.2) and in the Implementation Guidance. Quality considerations include things like the qualification of interpreters and how to make sure that information in different formats is correct.

☐ Yes
☐ No
☐ Not sure
☐ Prefer not to say

**12. If you have comments on the quality considerations we have included, please explain here.**

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**13. What do you think about the advice and support which we are planning to give to organisations?** This is outlined in the Consultation document section 12 and in the Implementation Guidance, especially section 7.

☐ The advice and support is about right
☐ The advice and support is too small
☐ The advice and support too big
☐ The advice and support is missing something
☐ The advice and support includes something it should not
☐ Prefer not to say

As set out earlier, we believe it would be helpful if resources accompanying the standard provides examples of best practice and also resources which could help professionals in training and their continuing professional development.

**14. We are planning to give organisations 12 months to implement the standard. What do you think about this?**

☐ 12 months is about right
☐ 12 months is too long
☐ 12 months is too short
☐ Prefer not to say

15. **What do you think about our plans for making sure that organisations follow the standard?** This is explained in section 13 of the consultation document and in section 17 of the Implementation Plan.

We believe that it will be important to ensure an external check on whether the standard is being met. We would support measures to involve the Care Quality Commission. We would ideally like to see involvement and feedback from disabled young people, as distinct from adults, as part of this process to ensure that their needs are being met.

We would suggest that it any organisation’s accessible information policy be **proactively** provided to any person after it has become apparent that they have a communication need. We would also suggest also that they receive a reminder about it every, for example, two years. We would be concerned that information about the policy may be ‘published’ but not be easy to find or that a deaf young person would not think to look for it unless their attention was drawn to it.

We also recommend that NHS England proactively promote the accessible information standard directly to deaf young people. We would be pleased to support efforts in this area.

16. **Do you have any comments on the Specification for the standard which are not included as part of other questions? If so, please include them here**.

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17. **Do you have any comments on the Implementation Plan for the standard?** If so, please include them here.

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18. **Do you have any comments on the Implementation Guidance for the standard or support for organisations?** If so, please include them here.

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19. **What do you think the impact of the standard will be?**

☐ Very good

☐ Good

- ☐ Neither good or bad (neutral)
- ☐ Bad
- ☐ Very bad
- ☐ Prefer not to say

20. **Due to the short timescales we have to read everyone's responses and make changes to the final standard, we have limited the space for 'free text'. If you have already given your views as part of the engagement phase, these have been considered in drafting the standard. If you do not feel that you have been able to share your views as part of this survey, please use the space below. We will try to consider any views you record in this section, but will not be able to respond or report on them in detail.**

The National Deaf Children's Society would be happy to work with the NHS on any of the above issues raised. We have already developed a range of resources for our My life, my health campaign which we would be happy to share. These resources are online at www.ndcsbuzz.org.uk/mylifemyhealth

We would also be keen to support measures to promote the standard to deaf children and young people and their parents.

We can be contacted at campaigns@ndcs.org.uk

Thank you for the opportunity to respond to this consultation.