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Supporting learners with healthcare needs: Draft guidance

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.

Although we do not have a response to all of the points outlined in the consultation document, there are several issues that we feel compelled to address. This relates specifically to 3 headline issues as follows:

Scope, intention and language used in the guidance

We welcome a clear focus on the processes used to establish what support is required as well as particular arrangements for individual learners. The focus on how learners should be supported to reintegrate in to the education setting following periods of absence is important for deaf children who have time away from school to receive cochlear implants (surgery and follow up habilitation).

We are concerned that statutory elements of this guidance do not apply to further education (FE) institutions. Whilst it might form a useful reference point for them in terms of best practice, we believe that learners in FE institutions must have the same statutory protections as those in maintained schools.

With reference to all sections of the guidance, it is important that the language is strengthened to ensure that rights are clearly conferred. Where the word "should" has been used, we contend that this ought to be amended to "must" in the majority of instances. This guidance would benefit generally from holding more statutory duties.

Section 4.11 of current guidance makes valuable reference to young people who require input from specially trained teachers. It is disappointing that this is not included in the draft guidance and we would encourage its inclusion in the

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final draft. Teachers of the Deaf make a valuable and specialist contribution to the learning and development of deaf young people. It is essential that this support is maintained for learners who are absent from school for protracted periods of time.

Current guidance also makes stronger reference to utilising the expertise of the voluntary sector, particularly in terms of sourcing appropriate information relating to specific medical conditions. It is important that the new guidance appropriately highlights the benefits of working with the voluntary sector and compels professionals to proactively engage with the sector for the benefit of the individual pupil. With this in mind, given our comprehensive resources for professionals working with deaf children and young people, we consider it essential that we are included in Annex 2 of the guidance.

Interaction with IDPs:

Whilst we welcome a focus on aligning considerations of healthcare needs with reference to impact on learning, we are keen that the use of IHPs does not detract from the importance of or in anyway take the place of IDPs, which will provide a much fuller picture of how disabilities impact on learning needs. We would recommend that where a young person has an IDP and an IHP, the IHP forms an amendment to the IDP.It is important that the IHP is not seen as a replacement for an IDP.

Similarly to existing legislation, the proposed new ALN Bill outlines that a child has ALN if s/he "has a disability which prevents or hinders him or her from making use of facilities for education or training of a kind generally provided for others of the same age in mainstream maintained schools or mainstream institutions in the further education sector." As such, every deaf child with a permanent hearing loss, or a child with a temporary hearing loss lasting more than 12 weeks (where grommet surgery is not sought), should automatically receive an IDP to ensure that they are afforded equality of opportunity in education. However, they might also benefit from a concurrent IHP to develop plans for maintaining specialist equipment such as hearing aids, for example, or to help plan for a child's return to school following a cochlear implant procedure.

Evidently the IHP has the capacity to address a range of issues, in particular with regard to technology, devices and the appropriate sharing of information which are addressed in more detail below. Whilst we acknowledge the importance and relevance of many aspects of the IHP we are keen to highlight that thought needs to be given to its intended interaction with IDPs both for the sake of clarity and because of the statutory nature of provisions made within IDPs.

We would propose that for children with an IDP, who also require an IHP, any recommendations or commitments made under the IHP are also included within their IDP. It is important that within each learning environment the professionals responsible for the development of IHPs and IDPs have a clear obligation to both communicate with one another and proactively share information about any health needs that may impact on learning. Currently the guidance does not achieve this.

Comments and recommendations on specific aspects of the guidance:

With regard to part e of section 2, we are concerned at the level of responsibility placed on parents to proactively inform schools about their child's specific healthcare needs. It is important that a duty is placed on healthcare providers to share timely and appropriately detailed information about all children and young people who have a healthcare need which could impact on their learning. We are concerned that parents may be unaware of IHPs and in some cases not best placed to communicate the potential implications of complex medical conditions. Parents must be fully engaged with as partners in the development of their child's

IHP. However, this should only be in so much as they feel able to be. There should not be an expectation placed on parents.

Whilst it is important for parents to be involved, the duty on healthcare providers needs to be clear and constant – not simply at specific points in an academic year or as part of a time-limited process. Communication must be ongoing.

We welcome the prioritisation of involving the learner in the development of their IHP. However it is important that the guidance acknowledges that in some cases, a young person will not have the mental capacity to make some decisions for themselves. NDCS Cymru would recommend the Fraser and Gillick competencies as a guide in this regard.

Considering part f of section 2, we feel that School nursing services could play a greater role in challenging the barriers that could be presented by supporting a learner with healthcare needs. Rather than simply offering advice, the school nursing service could provide a valuable sense check on modifications to ensure that risks are managed in a proportionate way.

We are pleased with a number of the provisions made within the "Sharing information" section of the guidance. In particular, it is positive that there is a clear obligation to communicate health plans to teachers, support staff and supply and temporary staff. This is particularly important and a provision that we feel should also apply to IDPs.

However, it is important to note that it would be useful to include reference to the need for staff to have a clear understanding of medical needs beyond medication. For example, it is important that teachers and support staff know how to change batteries in a hearing aid and be required to store replacement batteries. Although this is not a 'high risk' health need, a deaf child may be both significantly distressed and disadvantaged in terms of accessing learning opportunities if batteries are not replaced swiftly when they fail.

We welcome reference to providing appropriate training to ensure staff have appropriate understanding of healthcare needs. We would suggest that where a child uses any equipment or devices, such as hearing aids, radio aids or cochlear implants that there is a commitment to provide all staff who support that child with appropriate training on the use of those devices. It cannot be the responsibility of the child to manage the maintenance and use of devices essential to supporting their access to learning.

With regard to the section on integration, a number of the provisions set out in this section are particularly welcome. For example, the role of a liaison nurse to offer advice to prepare the learner's school on how best to manage their return. That being said, we are again concerned at the level of responsibility placed on parents to communicate with the school and highlight the need for mechanisms to be in place to ensure that parents are fully informed of what is expected of them and supported to achieve it.

We believe that any specific advice about modifications needed to support a learner, or advice about educational progress, must always form part of the learner's IDP in addition to their IHP. Where this information is acquired through processes associated with the development of an IHP there ought to be a duty for the individual responsible for that IHP to work with the ALNCO or other appropriate professional to ensure that the IDP is developed with access to all information.

In terms of insurance arrangements, we are aware that insurance has been an issue for some deaf learners in terms of assistive listening devices used for off-site activities. This needs to be addressed as a matter of urgency.

It is important that the medical equipment supplied is compatible with equipment used in education and home settings. It is important to compel providers to exercise partnership, prudence and demonstrate coproduction in terms of the procurement and servicing of all equipment. As technology rapidly changes, it is important to future-proof compatibility when making purchasing decisions. Currently there is not sufficient dialogue between health professionals and learning environments to ensure compatibility and to maximise the opportunities to improve a learners overall experience.

We welcome the obligation on governing bodies to publicise their setting's formal complaints procedure. However, we would add that they should also be obliged to proactively share this information with parents at the time an IHP is developed for their child.

It is important to note that an IHP can only be used to support children where a diagnosis has been made. For deaf children and young people, diagnosis can take time and in other cases symptoms can be missed. In order to ensure deaf children are identified early and able to access the support offered through both IHPs and IDPs, we would advocate a national hearing screening programme for all children in their first year of compulsory school.

The above detailed comments reflect a broad overview of our concerns and recommendations. We would be happy to provide a more detailed analysis of any elements of the guidance we have commented on above.

Should you require any further information, or if you would like to discuss our views on the guidance in more detail, please do not hesitate to contact me.

Kind regards,

Kate Cubbage Policy and Campaigns Officer