Consultation on Welsh Government guidance 'Supporting learners with healthcare needs'

Joint Organisation Response (see list below)

We are responding as a group of organisations on behalf of children and young people with medical conditions. The needs of this group are more complex and long-term than those with short term healthcare needs. The guidance relates to the broader concept of healthcare needs.

Key messages:

- 1. The guidance states clearly that providing support for medical conditions in schools is '....entirely voluntary' and that 'no staff member can be required to administer or supervise medication unless it forms part of their contract, terms and conditions or a mutually agreed job plan'.
- 2. There remains no clarification of the relationship between the guidance and the Bill/Code and whether or not the ALN Framework might apply to children with medical conditions. The Bill and Code must be amended to reflect the guidance to ensure seamless support. Neither the Bill nor Code make explicit reference to medical conditions. The Code refers to statutory guidance that contains explicitly voluntary duties. The guidance doesn't negate the need to amend ALN Bill and Code, rather intensifies and accelerates it.
- 3. The crossover with the current SEN system cannot be ignored. In the 49 page document, there are 29 references to the SEN system, including signposts and references to supporting guidance, legislation, practical examples, equipment and staff roles.

The impact on children and families cannot be understated. If there is no definitive action to amend the ALN Bill and Code, the new reforms will have disproportionately adverse effects on children and young people with long-term medical conditions in Wales. This vulnerable group, who are already at a significant health and education disadvantage, must be able to achieve their full potential in education. There is an urgent need to empower schools, families & LEAs to work collaboratively to put the right care in place.

Yours faithfully,

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whether you consider the Welsh Government's new statutory guidance 'Supporting learners
with healthcare needs' meets the calls received in evidence to the Committee to place the
healthcare guidance in Wales on a statutory footing;

(1) Use of Education Act 2002

The guidance has been issued under the Education Act 2002. The Education Act 2002 is a key piece of child safeguarding, welfare and protection legislation. Until now, the most recognised statutory guidance issued under the Act is entitled 'Keeping Children Safe in Education'

(https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/550511/Keep ing_children_safe_in_education.pdf).

As such, this is an unprecedented use of the Act and creates a fourth model for healthcare needs management in a school setting in the UK. In England, the Education Act 2002 was not used in this way and instead the Children & Families Act 2014 was passed, explicitly providing for medical conditions (and not healthcare needs generally). In Scotland, the additional needs system is used for long-term medical conditions, which includes a right of appeal to the Additional Needs Tribunal. In Northern Ireland, care in schools for medical conditions remains voluntary, supported by a condition-specific and comprehensive guidance document.

(i) Section 175

It appears that Section 175 of the Education Act 2002 has been misquoted in the guidance, resulting in the threshold for non-compliance being lowered for schools. The guidance quotes it as saying that: 'Local authorities and governing bodies must have regard to this statutory guidance.....'Must have regard' means to take account of this guidance and carefully consider it. Having done so, there would need to be a good reason to justify not complying with it.'

In reality, Section 175 lists the powers of LEAs and governing bodies to make arrangements for ensuring that their functions safeguard and promote the welfare of children. Its accompanying statutory guidance, 'Keeping Children Safe in Education' states that: 'Schools and colleges must have regard to (the statutory guidance) when carrying out their duties to safeguard and promote the welfare of children. This means that they should comply with it unless exceptional circumstances arise.'

This is very different from 'carefully consider' and 'need to be a good reason to justify not complying with it'. This would not target schools who refuse to engage with medical conditions. For example, a Head Teacher could disallow the attendance of a child with a medical condition because the person who usually provides the care is off sick. This could satisfy the threshold of 'good reason', as nobody would want a child to attend if it were dangerous to do so. It may not satisfy the threshold of 'exceptional circumstances'. Such contingencies are usually detailed in Individual Health Plans, which the guidance does not guarantee and which the ALN Bill does guarantee (via Individual Development Plans).

(ii) Section 21 (5)

Section 21 (5) relates to the promotion of well-being. The guidance refers to well-being throughout and uses the term interchangeably with 'health'. The terms 'health' and 'well-being' are different and well-established. Well-being legislation applies to all children and does not differentiate between a child with a healthcare need and one without.

(2) ALN Bill

The guidance doesn't negate the need to amend the ALN Bill/Code, rather intensifies and accelerates it. What will the relationship be between the ALN Bill and Education Act 2002? What is the relationship between the Code and the Guidance? We still have a situation whereby the Code refers to statutory guidance that contains explicitly voluntary duties.

We welcome the guidance's recognition of:

- The fact that provision for medical conditions in schools is inextricably linked with the current SEN system. In the 49 page document, there are 29 references to the SEN system, including signposts and references to supporting guidance, legislation, practical examples, equipment and staff roles.
- The impact of healthcare needs on learning. This is now established and clear in the document and is critical in aligning provision of care for medical conditions with the ALN framework.
- The distinction between short and long term needs are made but not with regard to resulting pathways of treatment or minimum standards of provision.

In conclusion, it is impossible for the guidance to work in isolation or for it to be considered in a silo as a 'new' statutory document.

 your early assessment on whether 'Supporting learners with healthcare needs' would sufficiently meet the healthcare needs of learners in Wales, and if not how the Bill could be used to help achieve this; and

(1) Guidance document

We welcome the editorial changes to the guidance, which address the linguistic ambiguity of the previous document. We welcome the strengthening of the language in the guidance, and note the following changes in the mentions of may, should, must in each document:

	Previous Draft	Final Draft
May	78 (24.2%)	65 (20.6%)
Should	210 (65.2%)	202 (64.1%)
Must	34 (10.5%)	48 (15.2%)
Total	322	315

Nevertheless there remain key concerns about the substance of the guidance from a long-term medical conditions perspective.

Voluntary: Emphasis & Impact

Page 9 of the 2017 document states that providing care for a child with healthcare needs is '....entirely voluntary' & that 'No staff member can be required to administer or supervise medication unless it forms part of their contract, terms and conditions or a mutually agreed job plan'.

The use of volunteers from existing school staff is commonplace in Wales and is part of a well-established and cost-effective model for all agencies involved in delivering care. Both the 2010 and 2017 guidance documents make it very clear that caring for a child with healthcare needs is voluntary and as such, the entire process of providing care is undermined and cannot be reconciled with this being on a 'new' statutory footing. The voluntary capacity means that some schools do not deliver support as they should.

No volunteers?

No reference is made to a scenario whereby no volunteers come forward. In practice, this is most likely to result in the following:

- (i) High levels of parental involvement: It is very common for families to have only one parent in employment so as to enable the other to visit the school to provide care. Sometimes this is as frequently as every two hours. Where a parent does work, it is commonplace for them to visit the school once a day during their own lunch hour to provide care. Some families advise that they have moved house to live closer to the school to be able to do this.
- (ii) The school will apply for funding to the LEA's SEN funding streams (School Action, School Action Plus, Statement of SEN or other types of 1-2-1 support). The SEN reporting in Wales shows those who are categorised as having physical/medical difficulties. In 2016, there were:

1,216 pupils with a statement of SEN 3,476 pupils with no statement Total = 4,692 pupils (4.5%)

2016 School Census Results, Statistics for Wales: Pupils with SEN in maintained schools by major need (Physical and medical difficulties)

(http://gov.wales/docs/statistics/2016/160727-school-census-results-2016-en.pdf)

This is not mentioned in the guidance nor is it included in the Additional Learning Needs & Education Tribunal (Wales) Bill and its accompanying Code of Practice. Local Education Authorities in Wales advise that the only available means of provision of funding and staff support is via ALN and/or Inclusion Team budgets. Obtaining funded support is challenging and those who are not successful are left with no alternative other than a high level of parental involvement or a child being unable to attend school.

Distinction: Disability or not?

There are brief references to some long term medical conditions being considered as disabilities under the Equality Act 2010. This crossover should be far more explicit. The guidance should recognise that this group should be signposted to the SEN/ALN system, if that is the intention, and should include provision for those that are not within the Equality Act definition. This

ambiguity could be addressed by the ALN Bill (explicitly state that medical conditions are within the Framework).

Complaints procedure:

The new complaints procedure (page 22) details exactly the ALN Framework dispute resolution pathway. This is a new and unexpected step in the right direction. Rights of Appeal to the Tribunal for medical conditions that are considered disabilities should be clarified in far more detail. The NHS and the Tribunal should be made aware of this new scope. This ambiguity should be addressed by the ALN Bill (Rights of Appeal extended to medical conditions).

If the above is a misinterpretation of the guidance, there is no mechanism for non-compliance of any party. Nor is there a complaints procedure for those healthcare needs that are not considered a disability.

Individual Health Plan (IHP):

The final decision on whether to create an IHP rests with the Head Teacher. The fact that long-term conditions are now mentioned in the guidance does provide a better footing for making the case of having an IHP in place, but this is still undermined and doesn't help if a school refuses to engage. This also raises issues of subjectivity & variability. This ambiguity should be addressed by the ALN Bill (Mandatory requirement that children with medical conditions have an IHP in place).

Medical Conditions Policy

The previous 2010 guidance is stronger in ensuring that a healthcare needs policy is in place. The ambiguity in the 2017 guidance should be addressed by the ALN Bill (Mandatory requirement to have a Medical Conditions Policy in place for medical conditions).

Other:

Some of the aspects of food management/allergies in the guidance are misleading and could cause confusion for schools in practice.

(2) How could the Bill be used to help achieve this?

In addition to the suggestions above, amendments to the ALN Bill/Code are required so as to refer to guidance adequately in the following ways:

- Distinction needs to be clear between healthcare needs generally and long term medical conditions that (1) impact on learning and are (2) disabilities.
- Crossover areas with the ALN Framework contained in the guidance are undeniable and need to be explicit in the Bill/Code. There are 29 mentions of disability/SEN support in the guidance document that the Bill/Code should make reference to. All quoted supporting guidance, documents and legislation signposts reader to the SEN system, its documentation and support. For more detail:
- 'Continuing Care Guidance 2012' signposts reader back to SEN framework as being the overarching consideration in delivering care.
- Page 21 of guidance signposts reader to 'SEN Code of Practice'.

- -'Learner Travel (Wales) Measure' does not contain any reference to healthcare needs. It includes a small and very brief reference to disabilities.
- 'National Reading & Numeracy Tests Test Administration Handbook 2017' does not contain any reference to healthcare needs, but contains information on disability access arrangement. It lists the groups as learners with a statement of SEN, those receiving provision via School Action/Plus and whose learning difficulty/disability significantly affects their access to the tests. It applies to those with disabilities who do not have SEN but who might require alternative access arrangements. Those with a long term medical condition will not always have access issues.
- Where references are made to specific groups, it is in the supporting documents that are quoted throughout. These refer to disability legislation and refer reader back to SEN system for clarification, provision and support with no mention of health needs.

your views on when a full assessment of 'Supporting learners with healthcare needs' could be undertaken to effectively assess its level of success.

Timings

We question how a full assessment of the guidance could take place as intended in the summer term of 2017 and as described by the Minister. We were made aware of the publication of the guidance by Assembly Members, however are not aware of the communication, distribution or implementation plan for the guidance. As such, any assessment of the guidance within a few months is untenable.

Methods

Based on data from one LEA area, we estimate that awareness of the 2010 guidance is at around 20% after 7 years in the public domain. Contact with relevant agencies across Wales suggests this is a generous estimate.

It is also important to note that it would be incredibly problematic to assess the guidance accurately or effectively for long-term conditions. This would require the removal or withdrawal of the SEN/ALN support system. Providing assistance to children whose needs are additional or different in schools is delivered by the same systems, processes, agencies, funding streams and staff roles in practice. We have been approached by LEAs who advise that they are providing support as per the additional learning needs system and will continue to do so for children with medical conditions. This beneficial provision of support cannot be attributed to the guidance.

As a comparison, the Children & Families Act came into force on 1st September 2014 in England and evaluation is only just beginning in earnest. There are crucial lessons for Wales. Evidence shows that good care at school is achievable if the right elements are in place as outlined above. We urge decision makers in Wales to take evidence-based anticipatory action to this end and reaffirm our offer of assistance, experience and evidence to the Committee.