1
Dear Sirs,

I hereby wish to submit the following comments on your Access to Education for Children / Young People with Medical Conditions Consultation:

What can I say? As a Mentor and Coach with the Royal Voluntary Service here in North Wales I think that it is IMPERATIVE that Children / Young People / Future Generations have FULL, TRANSPARENT & OPEN ACCESS to a good quality of education and learning in Welsh schools.

As a Bipolar 1 Sufferer (I've had it all my life) I have fully experienced the outright rather SHAMBOLIC nature of healthcare and education provision in many UK school(s). I managed to get a Degree and PGCert but had to work exceptionally hard on myself outside of the 'state system' to get my education. This should not be the case. Medical Conditions need to be highlighted much sooner in the school / healthcare systems and PSE Education should and could take the lead on this.

School pupils with medical needs need a better quality of delivery of health / social care / educational subjects and topics and support systems need to focus on a good quality, robust form of EDUCATION & EMPOWERMENT. Only then will pupils achieve and attain a successful education for themselves, and those around them, that is relevant to their needs, both medical and non-medical.

This concludes my comments and I look forward to being of further assistance if at all possible. Thank-you.

Best,
Regards,

Member of public – anonymous

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Ruth Ferrier

Organisation (if applicable): Vale of Glamorgan Education authority

email / telephone number: 01446709811

Your address: Provincial House, Kendrick Road, Barry,
Vale of GlamorganCF634RU

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	x
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The guidance document is clear and easy to understand. However one of the main aims of updating the guidance was to make it more concise. This document is still lengthy. A shortened version that includes just the main points with links to the full guidance would be extremely useful for busy professionals.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The revised draft is very clear in its presentation of legal duties in relation to schools, governors and local authorities.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The document is structured clearly and specific information is very easy to find. The inclusion of statutory duties in bold is particularly useful.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The guidance on the use of emergency salbutamol inhalers in schools does provide adequate advice to schools and local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers. The sections relating to the “early signs of an asthma attack, asthma procedures and practical steps following the use of the emergency inhaler” are particularly helpful to non-medical staff dealing with children.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The exemplar forms are sufficient for the needs of schools. However schools should not be encouraged to adapt the forms without medical advice.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The outline of the legal framework in annex 1 is helpful but all of the information should have been included in the body of the main guidance for the absence of doubt. Linking the guide to the Equality Act 2010 is very helpful.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:
The contacts list in Appendix 2 will enable schools to access further information, support and advice. The document could be improved by strengthening the responsibilities of parents.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

3

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Mrs Rebekah Watson

Organisation (if applicable): Migraine Action

email / telephone number:
rebekahwatson@migraine.org.uk

Your address:
4th Floor, 27 East Street
Leicester LE1 6NB

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
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Department for Education and Skills
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	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☒
	Individuals	☐

	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

Thank you for the opportunity to respond to this consultation document. We welcome the efforts to support learners with healthcare needs but we do feel that the proposed draft is insufficient.

The focus seems to be on protecting schools and LEAs; as opposed to supporting learners with healthcare needs. We feel that children's health needs, alongside the safeguarding and promotion of these needs, should be paramount. However, this is not demonstrated throughout the draft and we are concerned by the lack of standardised policies and procedures.

The document has an overwhelming tone of ambiguity and lacks clarity. The content is non-direct and there is no clear indication of staff roles, organisation requirements and how to deliver effective support. This lack of clarity must be addressed to ensure the best possible outcomes for learners with health needs. The current guidance framework has failed for many schools who are unwilling to change practice or improve support. This is likely to continue or worsen if the guidance remains unclear and open to interpretation.

We would also like to raise our concern regarding the proposed June 2016 deadline for completion of the document. We feel that there has been a lack of consultation with stakeholders around this issue, including the engagement of children and families of children with medical needs. Proper consultation is vital to ensure that learners with ***all*** health-care needs receive the right support.

In order to improve the existing framework, we recommend the following be put in place as a matter of urgency:

1. Statutory duty

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

We strongly feel that there is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs. This would bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** (not should) make additional arrangements for supporting pupils at schools with medical conditions.

We regularly refer to this framework when supporting parents and schools to ensure children with migraine receive the right support. The lack of explicit duty on schools in Wales makes it increasingly difficult to provide guidance and we feel this must be addressed.

2. A well-equipped and trained workforce

As well as introducing a statutory duty, there needs to be an adequate workforce to support its implementation.

There are currently issues with low awareness, misunderstanding and a lack of confidence around school staff managing medical needs. Schools regularly articulate their concerns regarding their legal position in caring for children with migraine and view the lines of responsibility as unclear with the current voluntary system. Many parents and health care professionals also raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs.

We therefore recommend that Welsh Government explores the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs.

3. Practical omissions

We strongly urge Welsh Government to revise the draft guidance document to include practical advice such as food management, recovery space and the need for every child with medical needs to have in place and Individual Health Plan (IHP). The guidance currently states that an IHP ‘may involve some or all of the following…’ This lack of clarity is insufficient and highlights the overall inadequacy of the draft.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These duties are not related to learners with healthcare needs". The IHP is given an 'optional' status (pg. 22) but this would be appropriate for any child with any health condition. On the contrary, the draft suggests that an 'accessibility' plan should be put in place; but this would not be relevant or appropriate for all children with healthcare needs.

Throughout the draft, there is inconsistent use of bold/non-bold text with regards to duties and/or suggestions. The document regularly uses terms such as 'if', 'whether' and 'could' – which suggest that the guidance is optional and lacks clarity.

Annex 2 includes 'useful contacts' but there is no contact information. We are also concerned that there is no mention of migraine as a health condition and no signposting to Migraine Action. Whilst we appreciate that not **all** health conditions can possibly be listed, this condition affects 1 in 10 children and is more prevalent than diabetes, epilepsy and asthma combined. We feel that this needs addressing.

There is a lack of clarity when referring to 'staff' in terms of which position or role this relates to. There needs to be clearer guidance on which staff member would be responsible to ensure that this can be put into practice with some degree of accountability.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We feel that consultation with those who might use the document is essential. The contents need to be segregated with much clearer sections and an inclusion of appendices with template documents (i.e. IHP).

The guidance document applicable to England, 'Supporting pupils at school with medical conditions' contains the following sections in a clear and concise manner:

(i) The production, adherence and review of a school's key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(ii) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(iii) Procedures for day trips, residential visits and sporting activities.
(iv) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(v) Staff training and support.
(vi) Unacceptable practice, liability and indemnity issues and complaints.

We feel that a similar structure would benefit this guidance and provide much more clarity.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

We are unclear what ‘Annex 3’ refers to. In the absence of this, we will provide feedback on the document entitled ‘forms’.

Form 1: ‘Contacting emergency services’. Page 2 directs staff to 999, whereas the guidance document signposts to NHS direct. This is unclear and contradictory.

Form 2: ‘Parental agreement for school/setting to administer medicine’. This may not be suitable for every condition and should be revisited.

Form 6: ‘Request for child to carry own medicine’. It is not clear which age group the form should be used for.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

We feel that language needs to be clearer to ensure that the guidance is sensical to a lay person. We would also raise concerns that the second paragraph contains several exceptions – this could lead to poor practice in multi-agency working and a potential lack of action.

Additionally, we are discontent that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is possible that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name:

Organisation (if applicable):

email / telephone number:

Your address:

Responses should be returned by **29 April 2016** to:

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	Teaching Unions	☐
	Local government	x ☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐

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	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	X ☐	**Neither agree nor disagree**	☐

Supporting comments

All learners are entitled to a full education – for KS3/4 does this mean a wide range of subjects?
Amount of EOTAS provision remains vague with no minimum hours allowing LAs to decide individually. This will lead to difficulties in the hospital.
No indication of who is responsible for the tuition when a learner is OOC for health reasons. Who funds this?
Post 16 learners – Do the learners need to start a qualification before 16 in order to continue with it post 16? Is this applicable for all qualifications?

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	X ☐	**Neither agree nor disagree**	☐

Supporting comments

No indication of who pays when a pupil is receiving EOTAS in another LA.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**X** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X** ☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X** ☐

Supporting comments

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	**X** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: /

Consultation Response Form

Your name: Denise Inger

Organisation (if applicable): SNAP Cymru

email / telephone number:
denise.inger@snapcymru.org
02920348990
07772896164

Your address: SNAP Cymru
10 Coopers Yard, Curran Road, Cardiff, CF10 5N

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	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The young person's thoughts and feelings must be taken into account when providing intimate care. There is no requirement in law for there to be more than one person therefore the young people's wishes and feelings must be taken into account.

SNAP Cymru would prefer the document to recognise that intimate care should not be overseen by two people if the young person is uncomfortable with this. Practise should be documented through Person Centred Planning.

The document should state that where medication is routine the people authorised to give the medication should never be all offsite at the same time. Also one of these authorised personnel must be available to go with the child / young person on offsite activities such as school trips.

A requirement is needed to ensure that work experience placements are aware of health care needs and that medication is supported.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties;

and general advice.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Some people find the bolding of text slightly more difficult read

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	x ☐	**Neither agree nor disagree**	☐

Supporting comments

Although two members of staff are required there is no requirement for them **not** to be absent from the school at the same time or for one of them to be available to accompany the child offsite such as on school trips. We would consider a line in the guidance for arrangements in the case of sickness and succession planning.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	x ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Very clear

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

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6

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Susan A Jones MBE
Lead Nurse School Health Nurs
Service

Organisation (if applicable): Abertawe Bro Mo
University Health Board

email / telephone number: susananne.jones@

01639 684412/07970453512
Your address:
School Health Nursing Service
1st Floor, Block A
Neath port Talbot Hospital
Port Talbot
SA12 7BX

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	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐

	Health professionals	x ☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Concise, easy to read and follow with unambiguous guidance that addresses and meets children and young people’s rights under UNCRC Articles: 3,4,5,6,12,13,19,23,24,28,29,31 & 32.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

This is well presented and highlighting statutory duties in bold throughout facilitates a flow of the text resulting in a logical and

structured therefore easy read.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Very clear headings to lead you to the appropriate section.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Very useful guidance but for absolute clarity it would be worth highlighting/ reinforcing this guidance only applies when a pupil <u>has a diagnosis of asthma</u> but the personal inhaler (that the school would already be aware of) is for whatever reason not available.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x** ☐

Supporting comments

This is for education colleagues to comment on as different professional responsibilities and accountabilities apply to them.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Very clear and unambiguous presentation of the facts

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

The IHP flowchart is particularly useful providing a clear explanation and identification of roles and responsibilities that will ensure schools are in a position to plan in advance to meet pupil's needs.

The realistic explanation of what is expected of an NHS School Nurse is welcomed professionally as to date this has been an issue in some LA areas.

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

7

Dear Sir or Madam,

I am writing to you regarding the above draft as a parent of a child with Coeliac disease and as a General Practitioner looking after 12000 patients (which includes children with Coeliac disease). I am also a member of Coeliac UK's Health Advisory Council and have participated in the cross party group on Coeliac disease and dermatitis herpetiformis, but the views I'm expressing here are my own.

Firstly, I was concerned to see that Coeliac UK are not represented in the list of relevant contacts in the draft proposal appendix. Coeliac disease prevalence rates are around 1% of the population. It is absolutely essential that patients with Coeliac disease adhere to a strictly gluten free diet (this also includes gluten free drink). Failure to do so can give rise to significant complications, such as osteoporosis, small bowel malignancy and poor weight gain and development to name but a few complications. Patients may also experience acute gastrointestinal upset and malaise as a result of gluten ingestion.

Upon reading the draft document - which I must say with the greatest respect - appeared vague and yet verbose without providing a concise and clear plan, it seemed to gloss over the very important role of diet in maintaining good health amongst sufferers of Coeliac disease. The treatment for children (& adults) with Coeliac disease involves strict exclusion of gluten from the diet. This impacts on school children in many ways. The most obvious consideration is in the provision of gluten free options for school meals - this could extend to facility to store gluten free staples brought in by pupils to be cooked (such as gluten free pasta) where options are not available on the menu - although, arguably in my opinion, this could and should be provided on the menu with a little planning and forethought. From personal experience, I can say that a simple system whereby my daughter's NHS Dietician liaised with a nominated dinner lady worked very well at primary school, but the situation appears woefully inadequate in secondary school.

Also, there needs to be consideration of the provision of gluten free snacks and, more importantly, that children with Coeliac disease are catered for when planning educational trips at home and abroad. Parents need to feel confident that gluten free food can be made available for children when staying away from home on school organised trips and that any accompanying responsible adult has a basic grasp of dietary requirements and restrictions. This is as important for Coeliacs as it is for other children requiring pharmaceutical rather than dietary treatment. Upon reading your draft, my impression is that this isn't covered in great enough detail, nor is the guidance issued sufficiently specific or robust from the perspective of patients with dietary medical requirements.

I am grateful to you for giving the opportunity to provide feedback and look forward to hearing how these points will be addressed

Yours sincerely Dr Geraint Preest

Sent from my mobile device

8

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Angela Phillips on behalf of All Wales HV/SHN forum

Organisation (if applicable): ABUHB

email / telephone number: angela.phillips@wales.co.uk

Your address: Oldway House , Gilfach St, Bargoed
CF81 8LQ

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	X
	Other public sector organisations	☐
	Third sector organisations	☐

	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	X	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The document makes it very clear that it is the responsibility of schools and governors to ensure that a IHP is in place and that this is done in partnership with the learner and parent.
More clarity could be provided in relation to the clinical advisor & trainer for a care plan. This should be the provider of the care/diagnosis as advised by the parent.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Page 8 SECTION (c) – Do not agree that ‘ all’ Learners with healthcare needs are linked to the School Nursing Service – This is unnecessary - only those that require School nurse support/advice or liaison.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The documents on the welsh government site should be appendix at the back of the final document or directly web- linked as templates - as difficult to follow the document without an example of IHP in hard copy.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x**

Supporting comments

As Q3
The documents on the welsh government site should be appendix at the back of the final document or directly web- linked as templates - as difficult to follow the document without an example of IHP in hard copy.

There appears to be a focus on children on medication. A IHP may be required for other medical treatments e.g. physiotherapy for Cystic Fibrosis, dietary / fluid specific information, mobility information. The documentation in Annex 3 does not lend itself to inclusion of such information very well. An exemplar care plan should be used as a template.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Annex 2: Useful contacts list is very helpful although tends to require regular updating due to frequent changes of services.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

9

Supporting Learners with Healthcare Needs

Consultation
Response Form

Your name: **HANNAH VERGHESE**
Organisation (if applicable): **THE MIGRAINE TRUST**
email / telephone number:
HVERGHESE@MIGRAINETRUST.ORG
Your address: **52-53 RUSSELL SQUARE, LONDON WC1B 4HP**

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
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	Local Health Boards	☐
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	Other public sector organisations	☐
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	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	X	**Neither agree nor disagree**	☐

Supporting comments

Reasons for responding to document
The Migraine Trust is the health and medical research charity for people living with migraine in the UK. As part of our work we provide information and advocacy support to young sufferers, and their families, via our support services. The support given to children with headache and migraine in schools is inconsistent. Many find that their condition has a negative impact on their education and is not understood. We believe that young sufferers need to have the same opportunities to fulfil their education as children without health needs and therefore welcome the opportunity to comment on the guidance.

Statutory/non-statutory duty
It is important that the guidance provides more clarity on what schools must do to deliver a safe learning environment for children with healthcare needs. There must be greater clarity on what schools are required to do rather than resting on a voluntary non-directive approach which leaves ambiguity and negates the usefulness of the document for parents and children. In the absence of a statutory duty on schools to support pupils with medical conditions in Wales, as there is in England under the Children and Families Act 2014, greater clarification from this guidance is essential to ensure that disengaged schools adhere. Many parents that contact The Migraine Trust are unable to convince schools to implement changes in practice and policies for children with headache and migraine despite the fact that this places those children at a disadvantage compared to their peers. This has a huge impact on young sufferer's educational attainment, confidence, behavioural problems and their ability to make friends. The guidance must be worded clearer so that there is no ambiguity on what schools must do e.g. every child with healthcare needs to have an IHP. It must be made clearer who is responsible and for what and when so that parents can make use of the guidance if a problem occurs.

Children must be at the heart of the document
Where parental/child engagement is championed in principle, it is often undermined in practice. On the one hand guidance suggests that "parents and learners should be active partners"(Section 2. P.12) and that it is unacceptable practice to "ignore the views of the learner or their parents/carers; or ignore

healthcare evidence or opinion"(Section 4.p 26). Yet the guidance lays out clearly that in the case of Individual Health Care Plans "if consensus cannot be reached, the head teacher should take the final decision". It is difficult to see how this is of help in the case of schools already failing to engage. Indeed we find no clear evidence from the document that learners with healthcare needs have been consulted as part of the process in formation of this document. Since they are a major stakeholder, more effort could have been made to engage patient and parent groups.

Fluctuating and Episodic Conditions

The document should explicitly state that children with fluctuating and episodic conditions are covered by the guidance and that any statutory requirements apply at all times not just when the child is experiencing ill health. Children with migraine take on average between 32 days and 3 months off from school due to their migraine compared to the general population who take between 3-13 days off (Abu-Arafeh, Headache Disorders – not respected, not resourced 2010). This can place them at a significant disadvantage compared to their peers. In between attacks children will appear well however they may require support, for example to catch up on work missed, manage triggers, take time off for medical appointments etc. We therefore suggest that the guidance is amended to ensure that schools are clear that children with health conditions that can result in frequent and short term absences, such as migraine, may also require learning, emotional and integration support. This is something that under the current system is not always addressed and must be strengthened in the content of the guidance.

Emotional Support

We think it is important that the social and emotional needs of children with health conditions are better addressed by the guidance. This should be taken into account in the individual healthcare plan to ensure that schools understand that these factors must be addressed as part of the support that they provide for the child. Schools should address these issues in line with their own policies e.g. bullying, where appropriate. It should not be presumed that schools will do this without clearer direction from the guidance.

Every Child to have an IHP

All children with healthcare needs should have an Individual healthcare plan. The detail and length of these will vary depending on the individual's needs (and may change at various points during the child's education). The wording of the guidance needs to be amended to ensure that no child with a health condition can be overlooked. We are particularly concerned that draft guidance explicitly makes clear that 'not all learner with healthcare needs require an IHP' and that 'the head teacher should take the final decision'. Parents of children with medical needs are left with no recourse when a school's leadership refuses to implement and IHP, even if it has been advised by health care providers and the parents themselves. Migraine is a fluctuating and episodic condition. Children often spend long periods of time well in between debilitating migraine attacks which may require them to leave school and/or be absent until the attack is over. Migraine is also a 'hidden' condition as there may not be obvious physical signs that a child is experiencing an attack. For this reason many children with migraine find that they are not believed in school, or are seen as truants or trouble makers and as such do not receive appropriate support by teachers and staff. Ensuring that all children with migraine and other health conditions have an individual healthcare plan in place is a positive step to addressing this.

Workforce Support

Whilst we recommend that a statutory duty be introduced, we recognise that this cannot work in isolation and needs to be supported by an adequate workforce. There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs. The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. How do we reconcile voluntary roles with the provision of effective support for a child with complex medical needs when away from home? The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises and where this is not viable, putting a child’s health and education at risk. In the case of migraine sufferers a lack of medication and/or appropriate action taken at the onset of an attack may miss opportunities to reduce its’ severity causing the child to miss more time at school.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	X ☐	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children’s rights throughout the remainder of the document.

The use of ‘bold’ font to imply information which has a legal duty is poor and does not focus the reader to the purpose of the document. It tends to suggest that anything not in bold is unimportant, which clearly is not the case. We would suggest removing the ‘bold’ font and replacing this with clear bullet pointed recommendation tables.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: “These duties are not related to learners with healthcare needs”.

The below examples are some of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to “enable the education setting to choose”, with no mention of what is appropriate for the needs and rights of children.
- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an ‘optional’ status by the draft on page 22.
- Throughout the draft, the inconsistent use of bold/non-bold text with regards to duties and/or suggestions is confusing. For example, on pages 6 & 7 there is an

interchangeable use of bold/non-bold text containing “must” duties as well as “should” suggestions. This occurs throughout the document.

- The existing suggestions of good practice have not changed since the 2010 guidance. As stated on page 3, these suggestions “may be required or desirable”. If this is the case, we would query the need to highlight them in bold in 2016 and would raise concerns over current schools practice if Welsh Government feels that this needs to be highlighted 5 years after the guidance was originally implementation.
- Further optional clauses are evident throughout the document i.e. “IHPs can help” on page 22, “whether to prepare an IHP”. The draft also contains ‘If’ clauses, such as ‘If a policy is in place, it should be followed’ – does this mean this is optional?
- Interchangeable language and terminology is used throughout when referring to “statutory guidance” and “legal requirements”.
- Page 23 begins mid-sentence.
- Annex 2 ‘Useful Contacts’ section contains no contact information and is not in alphabetical order.
- There are dangerous errors in the document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term ‘staff’ consistently throughout document i.e. page 11 ‘staff should be clear when a risk assessment is required’ with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on ‘other learners’ in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to ‘all necessary forms’ throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	X ☐	**Neither agree nor disagree**	☐

Supporting comments

We welcome the more concise nature of the new draft guidance compared with the 2010 document but would raise concerns over the structure of the content/sections. We would encourage a common-sense approach to the list of contents and would advise further consultation of those who might use the document, including parents and carers. Many of the third sector patient support groups/charities, who have a wealth of experience in producing parent/carer versions of guidance, would welcome the opportunity to be involved in this initiative.

The guidance document applicable to England, ‘Supporting pupils at school with medical conditions’ contains the following sections in a clear and concise manner:
(i) The production, adherence and review of a school’s key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(ii) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(iii) Procedures for day trips, residential visits and sporting activities.
(iv) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(v) Staff training and support.
(vi) Unacceptable practice, liability and indemnity issues and complaints.

The current draft is not written in a format suitable for parents and carers and consideration should be given to produce a more easy-to-read version of the document.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐		**Disagree**	☐	**Neither agree nor disagree**	**X**

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	**X**	**Neither agree nor disagree**	☐

Supporting comments

It is unclear which document Annex 3 is, as there is no such entitled document. In the absence of this, we will provide feedback on the document entitled ‘Forms’:

Form 1: ‘Contacting Emergency Services’. The information on page 2 directly contradicts the guidance document. Page 2 advises staff to contact 99 in an emergency, whereas the guidance document signposts staff to NHS Direct.

Form 2: ‘Parental agreement for school/setting to administer medicine’. This form may not be suitable for every condition and is very similar to an Individual Health Plan and so would be a duplication of paperwork. It may also be appropriate to include more than one contact details for family members.

Form 3: Clarity needed for those children who are able to administer medication themselves.

Form 4: ‘Record of medicine administered to an individual child’. A daily medicines log book is currently used which details the dosage given to a child. This form may seem long-winded for conditions that require regular medication and also duplicates existing paperwork.

Form 5: As above.

Form 6: ‘Request for child to carry his/her own medicine’. Would this form be completed for older/secondary school children? It is not clear which age group the form should be used for.

Form 7: ‘Staff training record – administration of medicines’. Will this form replace the existing sign off sheets that healthcare professionals complete with schools? The form currently has space for only one trained staff member, which would not be adequate (usually two or more staff members receive training).

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	X

Supporting comments

We would hope/expect to see the use of plain language and clear explanations given in any document explaining legal provisions. As such, we suggest that the opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. We would also raise concerns that the second paragraph contains several exceptions that provide gaps for inaction in multi-agency working. Additionally, we would raise concerns that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is likely that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions. For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

10

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Margaret Davies and Sue Halliwell

Organisation (if applicable): Estyn

email / telephone number: 02920 446523

Your address: Anchor Court, Keen Road, Cardiff CF24 5JW

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
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Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

It would also be helpful if the document included a summary of the statutory guidance at the beginning of the document to ensure clarity on roles and responsibilities for local authorities, governing bodies and schools.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

Structure and guidance (including statutory responsibilities and good practice) is clear for local authorities and schools.

However, further clarity on the role of management committees in pupil referral units (PRUs) would be helpful as they do not carry the same statutory functions as governing bodies especially on finance, staffing and buildings. Clear guidance in this instance would be helpful on which aspects of the guidance are local authority responsibilities and which aspects are delegated to the management of the PRU.

Also, the section on EOTAS learners clarifies the roles and responsibilities of supporting learners returning from hospital care. However, it does not cover the range of EOTAS provisions arranged for learners by the local authority. Further guidance on supporting learners with health care needs who attend alternative education provision, training providers or further education for part of their education would be beneficial.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Supporting documentation is very helpful. In addition, as with other guidance, a model policy would support a more consistent approach to meeting the needs of learners with healthcare needs.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

As previously noted, greater clarity on the role and responsibility of the Management Committee members of the PRU due to issues with budget, central appointments and management of buildings would be beneficial.

On page 6, further guidance would be helpful on the personnel that should be part of developing an individual health plan, especially for pupils with complex health needs. A greater focus on partnership working with specialist health colleagues will ensure a more robust health plan and greater monitoring role for the governing body.

On page 10 in relation to NHS Wales, the guidance assumes that all pupils attending local authority education provision are receiving equitable access to the NHS Nursing service. Specific guidance and monitoring of this aspect is required to ensure that vulnerable learners receiving home tuition, accessing a PRU or attending training providers (especially unregistered private providers) receive support from this service especially for sexual health advice, contraception and general health needs.
On page 14, specific advice on which medication is appropriate for pupils to carry in schools would be beneficial to avoid confusion and unnecessary tensions between schools and families, for example in relation to medication for mental health.

As previously stated, stronger guidance on meeting the health needs of learners attending provisions outside of maintained schools and hospital tuition is needed to ensure that all pupils regardless of educational needs are treated equitably.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

11

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Jane Darragh

Organisation (if applicable): CLIC Sargent

email / telephone number: 0208 752 2917

Your address: No 1 Farriers Yard, Assembly, London,
77-85 Fulham Palace Road, W6 8JA

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

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Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

CLIC Sargent is the UK's leading charity for children and young people and their families, providing clinical, practical and emotional support to help them cope with cancer and get the most of out life. Almost 2000 children aged up to 15 are diagnosed with cancer each year in the UK, with latest figures from the Wales Cancer Intelligence and Surveillance Unit showing that 71 0-14 year olds are diagnosed in Wales each year. Between 2012 and 2015 CLIC Sargent carried out specific research into children, teenagers and young people with cancers' experiences of education as part of a three year campaign on education. More information about this research and our campaign can be found here: http://www.clicsargent.org.uk/content/our-research

With nine in ten children telling us that cancer diagnosis and treatment made a difference to their school life, we know that children and young people with cancer face a number of barriers and challenges in keeping up with school work, feeling included in school life and fulfilling their potential. Some children and young people with cancer go through treatment with only minor disruption to their education, others are disadvantaged for years – their needs are very different and the education system must be flexible enough to provide effective support in all cases.

We welcome the Welsh Government's intention to improve and update the current guidance document for supporting learners with healthcare needs. However, we have some concerns that the new guidance does not include measures that will reduce variability in the provision of care or standardise policies and procedures for schools.

There appears to be a lack of progression since the 2010 guidance in increasing or improving support for children with medical needs at school. This means that access to education in Wales will continue to be variable and dependent on the school's approach.

Clarity of information is key. If the new guidance framework does not state precisely what schools **must** do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by a small number of schools who fail to support learners with healthcare needs appropriately. Children at these schools will therefore continue to be disadvantaged and parents will continue to be frustrated by guidance that is insufficiently specific or directive to assist them in meetings with schools where they have genuine concerns that their child is not being supported and is not safe.

The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties. In order to improve the existing framework, we recommend the following be put in place as a matter of urgency:

4. Statutory duty

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** (not should) make additional arrangements for supporting pupils at schools with medical conditions.

5. The ability to deliver in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce. There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. How do we reconcile voluntary roles with the provision of effective support for a child with complex medical needs when away from home? The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises and where this is not viable, put a child's health at risk. We think that the guidance should reference the designated school lead/named person for pupils with medical conditions.

We recommend that Welsh Government explores the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs.

6. **Practical omissions**

We would like the Welsh Government to revise the draft guidance document to include practical advice for supporting learners with healthcare needs to make it easier for schools to make adequate provisions.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child, although it could be argued that there is little reference to children's rights throughout the remainder of the document.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, states this on page 5: "These duties are not related to learners with healthcare needs".

The below examples are **some** of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.
- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22. Linked to this point, we do not think that the child's school will always be well placed to determine whether an IHP is required or not - this should always be a medical decision based on diagnosis. We welcome the

fact that an IHP should be developed in consultation with parents and children, however, we think that parents should also be able to request an ILP like they can with a statement of SEN or request an Education Health and Care Plan.

- Throughout the draft, there is an inconsistent use of bold/non-bold text with regards to duties and/or suggestions. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing “must” duties as well as “should” suggestions. This occurs throughout the document.
- The existing suggestions of good practice have not changed since the 2010 guidance. As stated on page 3, these suggestions “may be required or desirable”. If this is the case, we would query the need to highlight them in bold in 2016 and would raise concerns over what schools are currently doing if this needs to be highlighted 5 years after the guidance’ original implementation.
- Further optional clauses are evident throughout the document i.e. “IHPs can help” on page 22, “whether to prepare an IHP”. The draft also contains ‘If’ clauses, such as ‘If a policy is in place, it should be followed’ – does this mean this is optional?
- Interchangeable language and terminology is used throughout when referring to “statutory guidance” and “legal requirements”.
- Page 23 begins mid-sentence.
- Annex 2 ‘Useful Contacts’ section contains no contact information and is not in alphabetical order.
- There are errors in document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term ‘staff’ consistently throughout document i.e. page 11 ‘staff should be clear when a risk assessment is required’ with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on ‘other learners’ in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to ‘all necessary forms’ throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the concise nature of the new draft guidance but would raise concerns over the structure of the content/sections.

We would encourage a common-sense approach to the list of contents with possible consultation of those who might use the document.

The guidance document applicable to England, 'Supporting pupils at school with medical conditions' contains the following sections in a clear and concise manner:

(vii) The production, adherence and review of a school's key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(viii) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(ix) Procedures for day trips, residential visits and sporting activities.
(x) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(xi) Staff training and support.
(xii) Unacceptable practice, liability and indemnity issues and complaints.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

It is unclear which document Annex 3 is, as there is no such entitled document. We have not provided comments on this area.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

The opening paragraphs of page 27 do not go far enough in clarifying the legal provisions to a lay person and we would also raise concerns that the second paragraph contains several exceptions that provide gaps for inaction in multi-agency working.

We would also raise concerns that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is possible that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions.

For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

On page 16 of the guidance, it states the most common healthcare needs which will require training support. We think it is important to also reference some of the less common conditions, such as cancer, as examples of conditions where training or advice may be required. Although childhood cancer is rare it can have a huge impact on a child's education, with learners often having very complex needs. For example, CLIC Sargent research has found that a lack of understanding of cancer can lead to children falling behind and can lead to being bullied and left out of school activities[1].Schools and Local Authorities should be clear on how they would deal with such complex cases and how they would seek suitable training if the need arose.

We welcome the reference to reintegration throughout the guidance document, which is a key issue for children and young people with cancer. However, it's not clear whether the IHP will cover reintegration, and we think IHP's must include a section on reintegration. Without this there is a risk that schools might be unaware of the importance of this and children who have had a significant absence from school because of a medical condition may not receive the support they need to ensure a successful integration. The vast majority of children and young people with cancer do eventually return to school, however, they might find it difficult to reintegrate back into school like after their cancer treatment. Our 2012 research, 'No child with cancer let out', found that 56% of parents said their child found it difficult to readjust to school work and activities after returning to their primary school.

We also think that an example IHP template should be made available to schools to help them develop their own. A school policy template should be made available to schools to help them develop their own, in the absence of statutory guidance.

Lastly, it is particularly disappointing that there is no statutory guidance on ensuring children receive suitable education other than at school (EOTAS). We welcome the guidance on what schools and local authorities should do in this situation but without statutory guidance we are concerned that many children may have long absences from education, with provision patchy across schools and local authorities.

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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ndcs
every deaf child
Cymru

www.ndcs.org.uk

2 Ty Nant Court
Morganstown
Cardiff CF15 8LW

2 Cwrt Ty Nant
Treforgan
Caerdydd CF15 8LW

Tel/Ffôn 029 2037 3474
Text/Testun 029 2081 186
Fax/Ffacs 029 2081 4900
Email/E-bost
ndcswales@ndcs.org.uk
Freephone Helpline/
Llinell Gymorth Rhadffôn
0808 800 8880 (v/t)

Chief Executive/
Prif Weithredwraig
Susan Daniels OBE

President/Llywydd
Sir Christopher Benson
FRICS DL

22 April 2016

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 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

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Matt Tribbeck

Organisation (if applicable): N/A

email / telephone number: matthew.tribbeck@sky.com

Your address:

62 Park Place
Risca
Caerphilly
NP11 6AS

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	X

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

It should be noted in the guidance that administration of inhalers can have effects on other medication, which may require additional parental consent/contact or advice from health professionals. For example, it is common for diabetics to find salbutamol reduces the effectiveness of insulin.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 6 – Outline of the legal framework
Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Whilst generally supportive of the guidance and of the view that it is clear and well-devised, and hopefully of use to education staff in providing an equitable standard of learning to children with chronic health conditions, I feel the agreement by a member of staff to provide voluntary administration of medication will remain the key factor in whether this is achieved.

I have nothing but gratitude for the member of staff in my son’s school who has volunteered to administer his insulin; without this, no matter how clear or well-intentioned the guidance his chances of a full and equal opportunity to take part in nursery this would simply be impossible.

My son is a type 1 diabetic and requires more or less constant supervision and the ability to swiftly react to changes in his behaviour or activity that can affect his insulin regimen. In a healthy person, the pancreas carries out this task automatically 24 hours a day.

Those who care for my son will have this demand upon them for every moment he is in their care and I fully understand and respect the reluctance of some professionals to take on this additional level of responsibility. It is not an easy thing even for a parent to learn the correct administration of a potentially harmful drug and the signs a very young child requires medication. Again, I am lucky my son has a member of staff who is willing and able to do this in order that he can continue to attend nursery.

As such, whilst I welcome this new guidance my view is that the provision of an equitable learning experience to children with a chronic health care will remain premised on the availability of staff who are willing to offer the constant medical administration that I suspect accompanies such children in general. It is unfair to premise this on school staff members who are not from a medical background and I believe urgent thought should be given to increasing the numbers of trained support staff available to schools who can offer the specific medical support required if the aim of providing full and equitable participation is to have any meaning for children in Wales.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: **Rob Williams (Director of Policy)**

Organisation (if applicable): **NAHT Cymru**

email / telephone number: **cymru@naht.org.uk**
029 2048 4546

Your address: **9, Columbus Walk, Brigantine Place,**
Cardiff CF10 4BY

NAHT welcomes the opportunity to submit a response to the consultation. NAHT represents more than 29,000 school leaders in early years, primary, secondary and special schools, making us the largest association for school leaders in the UK. We represent, advise and train school leaders in Wales, England and Northern Ireland. We use our voice at the highest levels of government to influence policy for the benefit of leaders and learners everywhere. Our new section, NAHT Edge, supports, develops and represents middle leaders in schools.

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☒
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐

	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The principles behind the guidance are clear and provide common expectations. The language used within the document ensures that it is easily accessible for school leaders, governing bodies and relevant stakeholders.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

The legal duties are clear but the order in which they appear in the document could be improved (see response to Question 3)

There needs to be clarity for schools in order to ensure that they fully understand that it is at the school-level that they are delivering the statutory duty concerning supporting learners with healthcare needs that is actually placed upon Local Authorities.

It is helpful to refer to the safeguarding and promoting pupil welfare statutory duty of Governing Bodies.

It is also helpful to place key statutory guidance in bold.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

There is potential confusion due to the order that the information is presented.

The statutory duty lies with the Local Authority. However, in a practical sense it is a duty placed upon the Governing Body to deliver and, in turn, via delegation, is most likely to fall upon the school leaders and / or the Additional Learning Needs Co-ordinator to deliver at pupil level.

Placing the general principles at the very beginning of the document in which the role of the Governing Body is described first, is less helpful.
It would be clearer to use the text from Section 2 at the beginning of the document as it describes the general roles and responsibilities in order – Local Authority, Governing Body, Head teachers, Teachers / Support Staff, Parents / Learners, NHS Wales School Nursing Services

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The guidance is very clear and helpful.

The flowchart plan and additional letter and consent form templates are extremely useful.

It would be of interest to know how easily schools can access local support for training. Also how schools can address issues where no staff volunteer to be the named responsible person arises. This would provide evidence of the effectiveness of this policy in practice.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

NAHT Cymru acknowledge the need for flexibility in developing Individual Healthcare Plans that suit the needs of all learners in need.
However, given that increased risk periods for such pupils often occur when changing schools (including natural transition between phases) it would be helpful for pupils, parents, Local Authorities and Governing Bodies to operate a common, basic format.
The guidance already helpfully provides a list of suggested elements that could be included. By including a best practice example or a common, adaptable basic template it would ensure a degree of all-Wales consistency and mitigate the risks of a gap in healthcare when pupils move between settings.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

This section is clear and helpful but, for consistency with the response to Question 3, we would suggest the same order – Local Authority, Governing Body, The Equality Act, Other relevant provisions

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

15

Supporting Learners with Healthcare Needs

Consultation Response Form

Organisation: Governors Wales
E-mail: contact@governorswales.org.uk
Tel number: 029 2073 1546
Your address: Ground Floor, 3 Oaktree Court, Mulberry Drive, Cardiff Gate Business Park
Cardiff, CF23 8RS

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	X

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 2 – The format/presentation of the revised guidance document Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The guidance states that governing bodies have a responsibility to ensure that relevant staff have the necessary training, however, there is no mention of governors attending training. This will be crucial if there is a recommendation that governing bodies "*should ensure the arrangements identify the member of the governing body who has the overall responsibility for the development, monitoring and review of the healthcare needs arrangements*" (page 7).
It would be helpful to add "change of medication" to the list of documents for record keeping (page 13), which is mentioned earlier in the guidance to "*inform the education setting when medication changes or is discontinued, or the dose or administration method changes*" (page 10).
We also have a few concerns regarding the storage of medicines:

- **if the medication does need refrigeration, it would seem sensible for this to be held completely separate from domestic units (page 14).**
- security is paramount.

Most governing bodies have a checklist in place for the review of policies and whilst we agree that all policies, arrangements and procedures are regularly reviewed, there may not necessarily be a need to review the policy on an annual basis (page 21) but this would be for the relevant body to determine. IHPs would of course need to be reviewed as appropriate, based on individual needs.
The insurance arrangements section is particularly important (page 21)

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We note on page 11 that schools will want to ensure there are a reasonable number of designated members of staff to provide sufficient coverage. This could be very difficult in very small schools, particularly as this is voluntary.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

There in inevitably an overlap with other school policies, perhaps this should be mentioned.
Is there is timescale for schools to have the IHPs in place e.g. for new pupils admitted onto the school roll?

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Helen Thomas, Senior Policy Officer,

Organisation (if applicable): Information Commissioners Office

Information Commissioner's Office,
2nd Floor, Churchill House, Churchill Way,
Cardiff, CF10 2HH
Tel: 029 2067 8400
Email: wales@ico.org.uk

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

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	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	X
	Individuals	☐

	Other	☐

Background to the Information Commissioner's Office

The Information Commissioner has responsibility in the UK for promoting and enforcing the Data Protection Act 1998 (DPA), the Freedom of Information Act 2000 (FOIA), the Environmental Information Regulations and the Privacy and Electronic Communications Regulations. The Information Commissioner’s Office (ICO) is the UK’s independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals. The Commissioner does this by providing guidance to individuals and organisations, solving problems where he can, and taking appropriate action where the law is broken.

The ICO will provide a response only to consultation issues relevant to the scope of this office.

Comments on your draft guidance

Page 6. Local authorities

The third bullet refers to the Local Authority making arrangements to promote appropriate co-operation between the various organisations to provide suitable education. This paragraph could usefully include a reference to ensuring appropriate agreements are in place for data sharing, through the Wales Accord on Sharing Personal Information (WASPI) Information Sharing Protocols or Data Disclosure Agreements.

Page 7. Governing bodies

The fourth bullet should include reference to ensuring the school has up to date DPA policies and procedures, as the staff will need to be confident in handling and where appropriate sharing sensitive personal data to support learners with healthcare needs. Under the DPA, it is the governing body (of a maintained school) who are liable for breaches of the act.

[For information, in the course of our work with schools in Wales we have observed that many schools, particularly smaller ones, struggle with data protection, and would welcome clear guidance on issues such as handling requests for personal data, data sharing, IT security and records management. Many also request template policies as they do not have the capacity in house to produce school policies from scratch. It is not appropriate for the ICO as regulator to provide this level of policy detail, but we would be happy to support any national work by providing comments on drafts if the WG would find that useful.

The ICO currently offers a successful workshop to regional groups of school governors / head teachers in Wales help raise their awareness of their responsibilities under both the DPA and FOIA. We are able to run the workshop at no charge when a school / local authority acts as host and a mutually convenient date is agreed. Please contact the ICO at the Cardiff office (details below) for more information.]

Page 12. Sharing Information: Teachers and support staff

It is absolutely vital to support this and other policies that schools have good quality, up to date data protection policies and procedures that cover data sharing. Teachers and support staff must be aware of these policies and procedures, and receive regular training to ensure that they are confident in

their responsibilities for using personal data. The DPA protects the privacy of the individual, but it also supports and enables the sharing of personal information when it is necessary and legal to do so.
We are aware that as suggested here, some schools put sensitive personal data about pupils on staff notice boards, particularly when that

Page 12. Sharing Information: Parents and learners
The DPA emphasises the importance of ensuring that individuals (and in the case of children, this would include their parents or legal guardians) are given clear information about how their personal information is to be used, for example including who it will be shared with, and who to contact if they have any queries about the handling of their information, or would like a copy of it. This is known as “fair processing information” and is an important part of complying with the first principle of the Act. See the ICO website for more information: https://ico.org.uk/for-organisations/guide-to-data-protection/principle-1-fair-and-lawful/.

child has a high risk medical condition. This may not be the best example to use, as unless adequate safeguards are in place it is likely to constitute poor practice from a data protection perspective: information on a notice board can be seen by anyone who enters the room, regardless of their need to have access to the data. If a school is contemplating this approach it must have considered whether it is *necessary* to display the information in that way or whether there is another, more secure way of making sure that the relevant staff have the information they need. Explicit consent would also need to be obtained in advance from the individual or their parent /guardian.

With regard to secure intranet, this is likely to be a more effective means of ensuring the information is only shared with those who need to see it. However, the ICO has seen some breaches involving school intranets, so schools must ensure that the system is secure and that teachers have clear rules for use of passwords and access in classrooms etc to reduce the risk of sensitive information being breached. For example we have had cases where a child’s health information was inadvertently displayed on the classroom screen by a teacher for all the class to read, and cases where teachers have not used screen savers /passwords enabling students to easily access the system when the teacher is not watching. In some schools we are aware that the management information system is not securely separated from the teaching system, again increasing the risk that pupils can hack in or that teachers share in error.

Page 13. Record keeping
The list of records could also include:
☐ a copy of the fair processing information provided to the pupil / parents in relation to the health needs information,
☐ a copy of any explicit consent from the pupil /parents about sharing data with others – for example for school trips, or if the school feels that it is essential to put personal data on the staff notice board etc.
☐ A list of what information has been shared with whom.

Schools should have a clear retention policy setting out how long they need to keep these records, appropriate storage/security and ensuring there are appropriate provisions in place for the secure destruction of the information when it is no longer required, or its secure transfer to another organisation if appropriate.

The school should also keep a record of staff DPA and information sharing training. In the event of any breach investigation by the ICO, we would ask to see relevant policies, procedures and evidence that the relevant staff had received adequate, up to date training.

Page 16. Training

Please see comments above about the importance of staff having up to date training and guidance on data protection and information sharing.

Page 31. Useful contacts

Please would you add the following:

Data Protection
The Information Commissioner’s Office
Wales helpline: 029 2067 8400
https://ico.org.uk/for-organisations/education/

Please contact the ICO’s Cardiff Office on 029 2067 8400 if you would like to discuss any aspect of the above response.

26 April 2016

17

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name:
Dr Chris Bidder, Clinical Lead
Dr Justin Warner

Organisation (if applicable): Children and Young People's Wales Diabetes Network (& Brecon Group)

email / telephone number: Jon.Matthias@wales.nhs.uk / 02920 745073

Your address:
Children and Young People's Wales Diabetes Network (& Brecon Group)
c/o Cardiff & Vale University Health Board
Cardigan House
University Hospital of Wales
Heath Park
Cardiff
CF14 4XW

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

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	Education professionals	☐
	Teaching Unions	☐

	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☒
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

This response is from the Children and Young People's Wales Diabetes Network (CYPWDN)(and Brecon Group), an all-Wales clinical network that includes paediatric consultants and specialist registrars, paediatric diabetes specialist nurses, paediatric dietitians and child psychologists. Our members represent all 14 paediatric diabetes units in Wales, in six health boards, and between us we work with all 1,500 children who have diabetes in Wales. This response has been circulated within the network and it has been endorsed unanimously.

Many of our members interact regularly, often several times a week, with schools and so we believe we are uniquely placed to comment on how the medical needs of children should be met during school hours. We value our partnerships with school staff to ensure that children and young people with diabetes receive an excellent chance of living as normal a life as possible, which is one of the primary aims of the Welsh Government's Diabetes Delivery Plan.

Several members of the CYPWDN along with the charity Diabetes UK have already met with civil servants from education and health and the SCMO for Children's and Woman's health to discuss our concerns about the care of children with diabetes during the school day and have presented a briefing paper on this topic. Copies are available from our Network Co-ordinator – please email Jon.Matthias@wales.nhs.uk

We disagree that the revised draft Supporting Learners with Healthcare Needs guidance document is clear and easy to understand. We feel the proposed draft is disappointing.

The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales. We also feel it does not clearly set out the responsibilities for schools and staff working in education with regard to including children and young people with chronic illness, especially with reference to diabetes.

Instead there is a distinct focus on protecting schools and LEAs rather than safeguarding and promoting children's health and educational rights and needs. We have noted the draft explicitly protects school staff from having to take responsibility for a child's medical care, which we feel indicates a bias to the professional and does not place children's health at the heart of the document, which should be the motivation for this policy area.

In reading the draft Supporting Learners with Healthcare Needs, there is a distinct lack of progression since the 2010 guidance in increasing or improving support for children with medical needs at school. We therefore believe that the proposed draft guidance will produce the same variable and inequitable outcomes in access to education that currently prevail across Wales.

We are particularly disappointed at the lack of statutory protection for the rights of children and young people with chronic illnesses like diabetes to equal access to education. The law has changed in England to guarantee the rights of children with medical needs whilst they are at school. The Children and Families Act (England only) 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must (not should) make additional arrangements for supporting pupils at schools with medical conditions.

We believe there must be a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring Wales into parity with the English legislative system. It seems unfair that children in Wales do not have the same protection or guarantees. We would question why the medical needs of children in Wales are less important than the needs of children in England.

Clarity of information is key. Previous guidance has failed because of ambiguity across multiple areas. Evidence shows that a small number of disengaged schools ignore previous guidance because it was insufficiently direct and lacked clarity of roles, requirements and how to deliver effective support. The new guidance will fail if this lack of clarity is not addressed.

Contact with families demonstrates that some schools ignore the current guidance framework, are disengaged, and even when parents articulate concerns, are unwilling to change practice or improve support systems. This leads to poor care for children, dangerous situations where procedures and safety systems are not followed, and/or barriers to the child/parents feeling confident that the right care and expertise is in place. The current guidance framework has failed for these schools. It's voluntary, non-directive approach means that it is ignored. Many schools across Wales deliver good care and support. The Welsh Government has the opportunity to fine-tune the care these schools provide. The real challenge is how to improve support and care for schools which are disengaged and currently fail to deliver the right care.

There are many examples of schools that simply ignore the current guidance, schools that deliver unsafe practice and of disengaged staff who will not collaborate with parents to rectify poor practice. If the new guidance framework does not state precisely what schools must do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by this small number of schools. Children at these schools will be disadvantaged and parents will continue to be frustrated by Welsh Government guidance that is insufficiently specific or directive to assist them in meetings with schools where they have genuine concerns that their child is not being supported and is not safe. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties.

Furthermore, we would like to raise our concern regarding the proposed June 2016 deadline for completion of the document. We feel that there has been a lack of consultation with stakeholders around this issue, including the engagement of children and families of children with medical needs.

In order to improve the existing framework, we recommend the following be put in place as a matter of urgency:

7. Statutory duty

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must (not should) make additional arrangements for supporting pupils at schools with medical conditions.

8. The ability to deliver in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by training.

There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs. Schools regularly articulate their concerns regarding their legal position in caring for children with diabetes and view the lines of responsibility as unclear within the current voluntary system.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises and where this is not viable, put a child's health at risk. We would welcome the inclusion of healthcare professionals from local health boards in the list of stakeholders with responsibilities. The current reference to School Nurses ignores the fact that School Nurses are not present in many schools and are rarely involved with the treatment of diabetes or other chronic health conditions. Training for school staff is carried out by healthcare professionals, usually nurses, employed by local health boards. This must be recognised in the guidance with schools and parents encouraged to work in partnership with their local paediatric diabetes teams.

Evidence from families and schools indicates that there are not enough trained adults to provide an adequate level of care for children with medical needs in a school setting, despite the high level of support provided by NHS staff. Many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care. The training of supply teachers also presents difficulties.

We therefore recommend that Welsh Government explores the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs. An example of this is being piloted in Cardiff & Vale University Health Board with a qualified nurse working as a 'School's Educator' to train and advise school staff. This model should be included in the guidance as a recommendation for LEAs across Wales.

9. Practical omissions

We strongly urge Welsh Government to revise the draft guidance document to include practical advice such as food management, school transport and the need for every child with medical needs to have in place and Individual Health Plan (IHP). The current draft is inadequate.

We would be very happy to attend a meeting with Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance document.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These duties are not related to learners with healthcare needs".

Examples of inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.
- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22. We strongly object to the final decision on whether to develop an IHP resting with the head teacher as this is a healthcare issue. We would not expect members of our network to have a final say on educational issues.
- Throughout the draft, there is an inconsistent use of bold/non-bold text with regards to duties and/or suggestions. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing "must" duties as well as "should" suggestions. This occurs throughout the document.
- The existing suggestions of good practice have not changed since the 2010 guidance. As stated on page 3, these suggestions "may be required or desirable". If this is the case, we would query the need to highlight them in bold in 2016 and would raise concerns over what schools are currently doing if this needs to be highlighted 5 years after the guidance' original implementation.
- Further optional clauses are evident throughout the document i.e. "IHPs can help" on page 22, "whether to prepare an IHP". The draft also contains 'If'

clauses, such as ‘If a policy is in place, it should be followed’. Policies should not be optional.

- Interchangeable language and terminology is used throughout when referring to “statutory guidance” and “legal requirements”.
- Page 23 begins mid-sentence.
- Annex 2 ‘Useful Contacts’ section contains no contact information and is not in alphabetical order.
- There are errors in document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term ‘staff’ consistently throughout document i.e. page 11 ‘staff should be clear when a risk assessment is required’ with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on ‘other learners’ in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to ‘all necessary forms’ throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the concise nature of the new draft guidance but would raise concerns over the structure of the content/sections.

We would encourage a common-sense approach to the list of contents with possible consultation of those who might use the document.

The guidance document applicable to England, ‘Supporting pupils at school with medical conditions’ contains the following sections in a clear and concise manner:

(xiii) The production, adherence and review of a school’s key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(xiv) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(xv) Procedures for day trips, residential visits and sporting activities.
(xvi) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(xvii) Staff training and support.
(xviii) Unacceptable practice, liability and indemnity issues and complaints.

We welcome the list of unacceptable practices on page 26 but would like this to made clear that it is unacceptable to allow any of these scenarios to occur. Currently the wording is woolly and there is no firm commitment to ensure these examples of discrimination are prevented. In its current form we are sceptical that without statutory and mandatory underpinning these unacceptable practices would be prevented.

We believe this list could be reversed as a series of positive statements e.g. ‘We aim for all learners with healthcare needs to attend mainstream education, unless this would cause harm to the learner’. This list could then lead the document as a sequence of aspirations which all schools in Wales should seek to meet.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Forms already exist for use by healthcare professionals, schools and families to agree on care and procedures for the safe and effective treatment of diabetes. We would like to see a recommendation in the guidance that schools seek advice from their local paediatric diabetes team.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

We would expect to see the use of plain language and clear explanations given in any document explaining legal provisions. As such, we suggest that the opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. We would also raise concerns that the second paragraph contains several exceptions that provide gaps for inaction in multi-agency working.

Additionally, we would raise concerns that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is possible that they will be inadequate and unfit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions.

For example, the draft refers the reader on to the Learner Travel (Wales) Measure

2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

As previously mentioned, we believe there must be statutory and mandatory protection of the rights of school children in line to the protection given to children in England under the Families Act.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

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18

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Anwen O’Leary/Sarah Staveley

Organisation (if applicable): Children’s Continuing Care Team, Betsi Cadwaladr University Health Board

email / telephone number:
Anwen.O’Leary@wales.nhs.uk
Sarah.Staveley2@wales.nhs.uk
01745 583910 ext 2595
Your address:
Rhuddlan centre, 7 Vicarage Lane, Rhuddlan LL18 2UE

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	X ☐
	Other public sector organisations	☐
	Third sector organisations	☐

	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

No reference to the Children's Continuing care guidance (2012).

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x** ☐

Supporting comments

Standardised documentation contributes to more effective continuity of care.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x**

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

1. A child with a gastrostomy/PEG may require feeding or the administration of medication within the school day. These children maybe in a main stream or special school environment. There is no reference to this issue within the consultation document. There needs to be clarity as to the delegation of this task with regard to individual health care needs planning.
2. Page 7 last paragraph. Should reference Data Protection Act 1998. “in compliance with the Data Protection act 1998 and the learners right to privacy”
3. Page 10 (f) Where school nurses are referenced there should be reference to specialist nurses also.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Emma Williams

emmaem26@btinternet.com

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
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	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

Our child has Type 1 diabetes.

I was pleased to learn that the Welsh Government is going to update its guidance for providing care to children with additional medical needs and looked forward to seeing the new draft. I'm pleased to see certain useful sections included in the draft but I'm unsure whether this changes or improves the current situation.

I'm aware that the law has changed in England to guarantee the rights of children with medical needs whilst they are at school. Will this be happening in Wales, too?
It seems unfair that our children don't have the same protection or guarantees. English schools now have to make additional arrangements for children with health conditions. Why not in Wales? Are the medical needs of our children in Wales less important?

It isn't clear where we as parents can go if we are having problems with a school. Sometimes we have issues that we try and sort out ourselves but this is not easy and it takes a lot of co-ordination between us, the school and nurses to make sure that our child is getting the right care. The draft doesn't say who is responsible for what and when, which could lead to nobody doing anything and us as parents plugging the gap. When we have meetings with the school, it would be great if we could have clear guidance on who should be doing what etc. The whole process can be really stressful and it shouldn't have to be. Any parent will tell you that sending their child off to school (especially in the early days) is a worrying and stressful period that can be upsetting. Adding on a chronic condition that impacts on daily life compounds that worry.

Let's do the best that we can do for children in schools in Wales.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

As a parent, I'm not quite clear on who is responsible for what from reading the guidance. For example, when talking about schools, the draft keeps mentioning 'staff' without saying which staff (there are a few different people involved in my child's care at school). What happens when staff move on, when they are absent or when my child moves up to the next class? These things need to be clearer. There is no mention of one to one support staff for children with complex medical needs, such as Type 1 Diabetes. It would be very unsafe to let my young child go to school without constant monitoring, and I would refuse to let him attend school without his one to one assistant there. My son is 7 years old, he is far too young to be independent with his medical needs, he needs constant supervision as his blood levels fluctuate rapidly, requiring action immediately. A teacher is not in a positon to offer the level of care that he requires.

It seems a bit confusing and the bold/non-bold text for different duties doesn't make sense. Some sentences say that a school must do something and then others say that it should do something. I found the bold/non-bold parts didn't differentiate from each other in some places, so which is it? There are also some confusing sentences that say some duties are optional, such as having an IHP in place. How can an IHP be optional? Are risk assessments or health and safety requirements in the work place optional?

Again, it doesn't include much practical advice that we can transfer over to our day-to-day contact with the school/governing body/local authority. Who is responsible for ensuring that our children are safe in school, or between school and home i.e. school transport? Who should parents go to if we have concerns?

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

I think that the length of the document is fine.

Having said that, the document doesn't flow naturally. The draft doesn't contain much practical advice that we could transfer into day-to-day school life situations i.e. food management or school transport issues. In this sense, the document is quite vague and is not detailed enough. Did parents and teachers have input into the development of the draft?

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

Form 1: ‘Contacting Emergency Services’. The information on page 2 directly contradicts the guidance document. Page 2 advises staff to contact 999 in an emergency, whereas the guidance document signposts staff to NHS Direct, which isn’t an emergency service. This is really worrying!

Form 2: ‘Parental agreement for school/setting to administer medicine’. This form seems like the Individual Health Plan and so would be a duplication of paperwork. It would be better (and maybe safer) to have space for more than one contact, in case the school is not able to reach one of us.

Form 3: Dosage of insulin can change daily depending on mood/exercise/diet so you wouldn’t be able to put a definite answer here.

Form 4: ‘Record of medicine administered to an individual child’. At the moment, we use a daily medicines log book so this form may duplicate that. This log book is the one provided by Diabetes UK, is really useful and is passed between home and school every day.

Form 5: As above.

Form 6: ‘Request for child to carry his/her own medicine’. Would this form be completed for all children, regardless of age? It is not clear which age group the form should be used for.

Form 7: ‘Staff training record – administration of medicines’. Will this form replace the existing sign off sheets that healthcare professionals complete with schools? The form currently has space for only one trained staff member, which would not be adequate (usually two or more staff members receive training). It would also be useful for the form to include a ‘Parents/healthcare professional’ copy.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

I think it’s a good idea to include these, but they seem quite complicated and don’t explain in real life examples how the law helps my child (with regards to their diabetes).

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:
It is very worrying and ridiculous to consider a child with Type 1 Diabetes should take care of themselves. The condition has clearly not been investigated fully, and the level of severity that can happen with this condition is huge. More needs to be put in place to support these children in an already very challenging position. The teachers should not be placed under pressure to look after the complex needs of my child, and they would not be able to give him the level of support that he requires. It would put him in a very dangerous position if multiple staff members were allocated to his needs, as mistakes could be made, leading to possible insulin overdoses with catastrophic effect. It needs to be clearer in the guidelines that the child will receive one to one support if they need it, as my young son clearly does.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Sara Moran

Organisation (if applicable): Diabetes UK Cymru

email / telephone number:
sara.moran@diabetes.org.uk / 02920 668276

Your address:
Castlebridge 2
Cowbridge Road East
Cardiff CF11 9AB

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
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	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☒
	Individuals	☐

	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

Many thanks for being able to comment on this consultation document ‘Supporting Learners with Healthcare Needs’.

In general, we disagree with the proposed draft and find the content disappointing, as it fails to address both ‘learners’ and their ‘healthcare needs’ during the school day. The document appears to have been written very much from an education point of view and lacks clarity about the rights of a child during the school day who has healthcare needs that require input from school staff.

Tone & Language

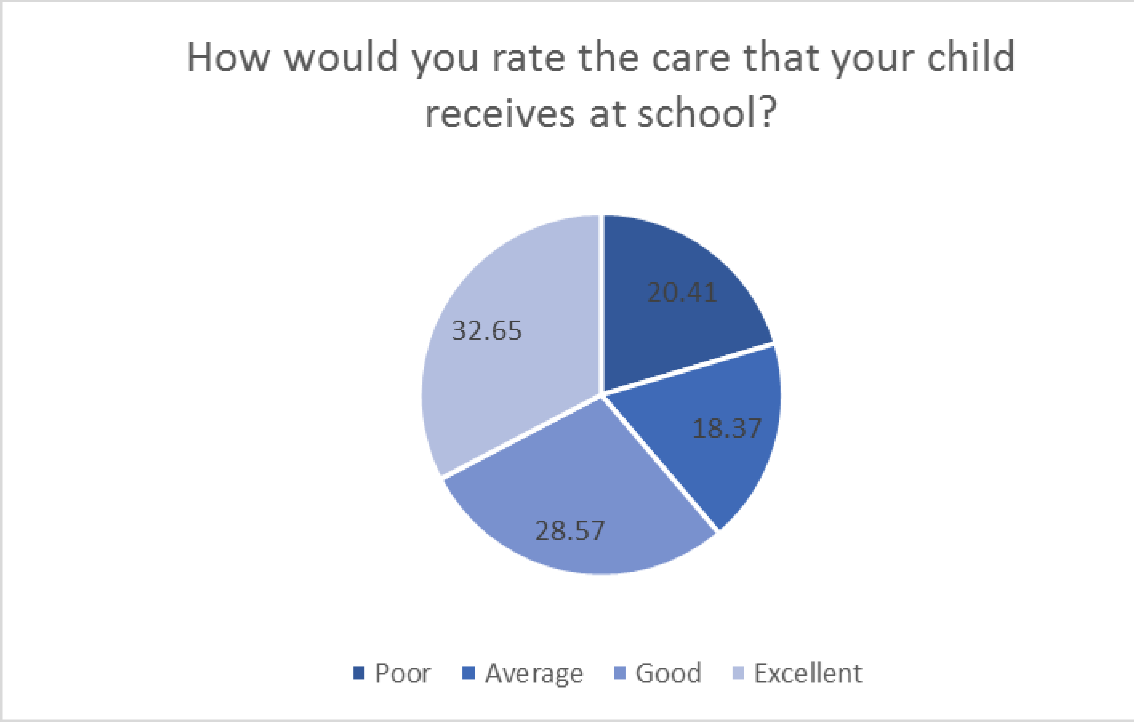
The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales. The draft does not place children at the heart of the document, which should be the motivation for this policy area.

Where parental/child engagement is championed in principle, it is often undermined in practice. On the one hand guidance suggests that “parents and learners should be active partners”(Section 2. P.12) and that it is unacceptable practice to “ignore the views of the learner or their parents/carers; or ignore healthcare evidence or opinion”(Section 4.p 26). Yet the guidance lays out clearly that in the case of Individual Health Care Plans “if consensus cannot be reached, the head teacher should take the final decision”. It is difficult to see how this is of help in the case of schools already failing to engage. Indeed we find no clear evidence from the document that learners with healthcare needs have been consulted as part of the process in formation of this document. Since they are a major stakeholder, more effort could have been made to engage patient and parent groups.

Outcomes

Whilst we welcome the Welsh Government's intention to improve and update the current guidance document for managing chronic diseases in schools, we would expect new guidance and its accompanying framework to adopt measures that will reduce adverse variability in provision of care and that will standardise policies and procedures for schools as much as possible in a move away from the current voluntary framework.

In reading the draft Supporting Learners with Healthcare Needs, there is a distinct lack of progression since the 2010 guidance in increasing or improving support for children with medical needs at school. We therefore believe that the proposed draft guidance will produce the same variable and inequitable outcomes in access to education that currently prevail across Wales. Diabetes UK Cymru's recent report, *Type 1 diabetes in schools in Wales – "An Excellent Chance"* evidenced the variable results produced by the current guidance framework. A survey of 59 families of children with Type 1 diabetes found that although 60% of families rated school care as 'Excellent' or 'Good', almost 40% rated it as 'Average' or 'Poor'.



When asked if they had ever had any issues with the care provided by their child's school, just over half (51%) of respondents advised that they had previously or currently had an issue.

Clearly, many schools across Wales deliver good care and support. The Welsh

Government has the opportunity to fine-tune the care these schools provide, to learn from them and to share best practice so that all children receive equitable school care.

The real challenge is how to improve support and care for schools who are disengaged and currently fail to deliver the right care.

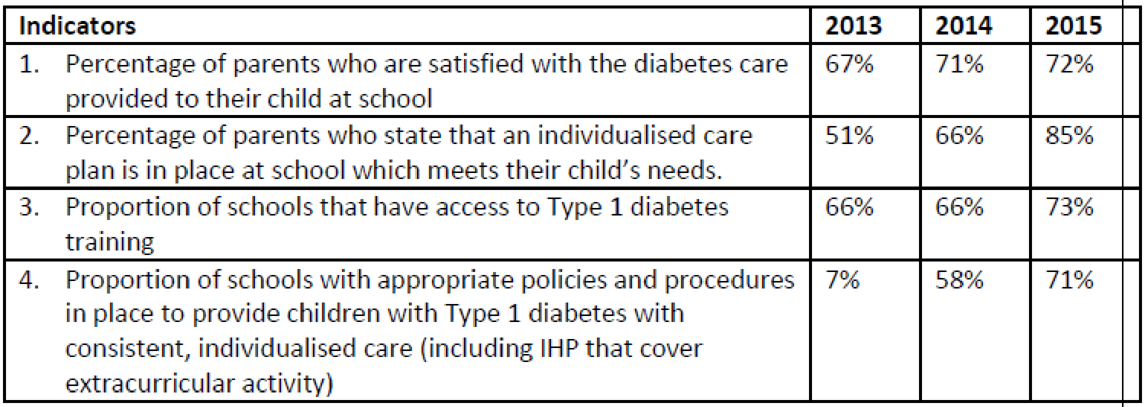
In order to improve the existing framework, we recommend the following be put in place as a matter of urgency:

10. Nature of the duty: Statutory duty or Non-statutory duty?

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** (not should) make additional arrangements for supporting pupils at schools with medical conditions. Central to this is the provision that **all** children with medical needs receive an IHP. We are particularly concerned that draft guidance explicitly makes clear that ‘not all learner with healthcare needs require an IHP’ and that ‘the head teacher should take the final decision’. Parents of children with medical needs are left with no recourse when a school’s leadership refuses to implement an IHP, even if it has been advised by health care providers and the parents themselves.

Whilst the implementation of the legislation in England is in its infancy, early indicators document a clear increase in schools’ engagement with medical conditions. Comparative evidence gathered annually by Diabetes UK shows that the situation in England is improving year on year:



Indicators	**2013**	**2014**	**2015**
1. Percentage of parents who are satisfied with the diabetes care provided to their child at school	67%	71%	72%
2. Percentage of parents who state that an individualised care plan is in place at school which meets their child’s needs.	51%	66%	85%
3. Proportion of schools that have access to Type 1 diabetes training	66%	66%	73%
4. Proportion of schools with appropriate policies and procedures in place to provide children with Type 1 diabetes with consistent, individualised care (including IHP that cover extracurricular activity)	7%	58%	71%

*Figures from 2013, 2014 and 2015 annual surveys of parents and schools conducted online by Diabetes UK. Please refer to page 30 of *Type 1 diabetes in schools in Wales – "An Excellent Chance" (Appendix E)* for more information.

Previous guidance in Wales has failed because of ambiguity across multiple demonstrable areas. Evidence shows that it's voluntary, non-directive approach means that it is ignored by a number of disengaged schools because it was insufficiently directive, lacked clarity of roles and failed to set out basic requirements in delivering effective support. The new guidance will fail if this is not addressed. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties. As a UK-wide organisation, it is much more difficult to provide assistance and guidance to supporters in Wales, where there is no explicit duty on schools which covers medical needs.

Contact with families demonstrates that even when parents articulate their concerns to schools, some are unwilling to change practices to improve support systems. This leads to poor care for children and dangerous situations where procedures and safety protocols are not followed (please see evidence presented in pages 15 – 17, *Type 1 diabetes in schools in Wales – "An Excellent Chance"*). These children are at a disadvantage and are likely to achieve worse health outcomes at an increased cost to them and to the NHS. Parents will continue to be frustrated by Welsh Government guidance that is insufficiently specific and directive in assisting them in meetings with schools where they have genuine concerns that their child is not safe and is not being supported. The impact on families is significant, with both children and parents lacking confidence that the right care and expertise is in place.

If the new guidance framework does not state precisely what schools **must** do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by a number of schools. We fail to see how the proposed guidance makes any clearer what measures are required to be put in place in order to adequately support learners with healthcare needs and with whom the responsibility lies to ensure such measures are implemented.

11. The ability to deliver in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce.

There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs. Schools regularly articulate their concerns regarding their legal position in caring for children with diabetes and view the lines of responsibility as unclear with the current voluntary system.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. How do we reconcile voluntary roles with the provision of effective support for a child with complex medical needs when away from home? The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises and where this is not viable, put a child's health and education at risk. *Type 1 diabetes in schools in Wales – "An Excellent Chance"* presents clear evidence of this (page 17). For example, 62% of respondents have stayed at home from their own work because of issues relating to their child's diabetes and 53% of respondents have had to leave their own work place during working hours to attend their child's school but some of those same respondents believe that the care at their child's school is good or excellent. The results suggest that parental involvement is not on a one-off basis, but is a regular and relied-upon routine with them having to provide regular and sometimes daily treatment for their child. As well as attending the school to inject insulin, 62% of parents advised that they are being relied upon to carry out other diabetes related tasks. 26% of these include supervising their child's diet or meal times at school. Some families described how they have had to attend the school in person to provide a small snack to their child because the school has refused to do so.

Further evidence from families and schools indicates that there are not enough trained adults to provide an adequate level of care for children with medical needs in a school setting, despite the high level of support provided by NHS staff and Paediatric Diabetes Specialist Nurses (PDSNs). For more detailed information on time spent visiting schools by PDSNs, please see page 18 of *Type 1 diabetes in schools in Wales – "An Excellent Chance".*

Many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care. The training of supply teachers also presents difficulties.

We therefore recommend that Welsh Government explores the implementation of any new guidance with the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs. In some circumstances, this could be achieved by a new directional role of the school nurse. Cardiff & Vale University Health Board have realised the need for further investment in a schools Diabetes Educator role and have funded a post until April 2017. This role aims to reduce variability in care during the school day by enhancing the understanding and improving the confidence of school staff who are providing this support.

12. Practical omissions

We strongly urge Welsh Government to revise the draft guidance document to include practical advice that relates specifically to children with medical needs. For evidence on common practical issues faced by families of children with Type 1 diabetes, please refer to pages 14-18 of *Type 1 diabetes in schools in Wales – "An*

Excellent Chance". These include children being sent home/withdrawn from the school day, as well as being excluded from after-school activities, sports, school trips (both off-site and residential) amongst other examples. Diabetes UK also regularly hears from parents whose children have been excluded from rewards/benefits linked to attendance because of diabetes related appointments.

In particular, we are concerned that there is little to no reference to the importance of food management or medical equipment as vital elements of support for many children with medical needs, both in the context of emergency and non-emergency chronic conditions.

We would also like to emphasise the need for every child with medical needs to have in place and Individual Health Plan (IHP). The current draft is inadequate in this respect.

Timeline

Furthermore, we would like to raise our concern regarding the proposed June 2016 deadline for completion of the document. We feel that there has been a lack of consultation with stakeholders around this issue, including the engagement of children and families of children with medical needs. As a third sector organisation listed throughout the consultation and draft documentation, we were surprised that we were not notified of the launch of the consultation. The lack of communication regarding this consultation means that we now have a short time period for responses and there is an increased risk that Welsh Government will not receive as wide a response to this consultation as is merited.

We would be very happy to attend a meeting with Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance document.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The use of 'bold' font to imply information which has a legal duty is poor and does not focus the reader to the purpose of the document. It tends to suggest that anything not in bold is unimportant, which clearly is not the case. We would suggest removing the 'bold' font and replacing this with clear bullet pointed recommendation tables.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These duties are not related to learners with healthcare needs".

The below examples are <u>some</u> of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.
- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22.
- Throughout the draft, the inconsistent use of bold/non-bold text with regards to duties and/or suggestions is confusing. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing "must" duties as well as "should" suggestions. This occurs throughout the document.
- The existing suggestions of good practice have not changed since the 2010 guidance. As stated on page 3, these suggestions "may be required or desirable". If this is the case, we would query the need to highlight them in bold in 2016 and would raise concerns over current schools practice if Welsh Government feels that this needs to be highlighted 5 years after the guidance was originally implementation.
- Further optional clauses are evident throughout the document i.e. "IHPs can help" on page 22, "whether to prepare an IHP". The draft also contains 'If' clauses, such as 'If a policy is in place, it should be followed' – does this mean this is optional?
- Interchangeable language and terminology is used throughout when

referring to “statutory guidance” and “legal requirements”.

- Page 23 begins mid-sentence.
- Annex 2 ‘Useful Contacts’ section contains no contact information and is not in alphabetical order.
- There are dangerous errors in the document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term ‘staff’ consistently throughout document i.e. page 11 ‘staff should be clear when a risk assessment is required’ with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on ‘other learners’ in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to ‘all necessary forms’ throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the more concise nature of the new draft guidance compared with the 2010 document but would raise concerns over the structure of the content/sections.

We would encourage a common-sense approach to the list of contents and would advise further consultation of those who might use the document. Many of the third sector patient support groups, who have a wealth of experience in producing parent/carer versions of guidance, would welcome the opportunity to be involved in this initiative.

The guidance document applicable to England, ‘Supporting pupils at school with medical conditions’ contains the following sections in a clear and concise manner:

(xix) The production, adherence and review of a school's key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(xx) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(xxi) Procedures for day trips, residential visits and sporting activities.
(xxii) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(xxiii) Staff training and support.
(xxiv) Unacceptable practice, liability and indemnity issues and complaints.

The current draft is not written in a format suitable for parents and carers and consideration should be given to produce a more easy-to-read version of the document.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

It is unclear which document Annex 3 is, as there is no such entitled document. In the absence of this, we will provide feedback on the document entitled ‘Forms’:

Form 1: ‘Contacting Emergency Services’. The information on page 2 directly contradicts the guidance document. Page 2 advises staff to contact 999 in an emergency, whereas the guidance document signposts staff to NHS Direct, which is not an emergency service.

Form 2: ‘Parental agreement for school/setting to administer medicine’. This form may not be suitable for every condition and is very similar to an Individual Health Plan and so would be a duplication of paperwork. It may also be appropriate to include more than one contact details for family members.

Form 3: Dosage of insulin may change daily depending on mood/exercise/diet so it wouldn’t be appropriate to put this in as a relevant permanent dose.

Form 4: ‘Record of medicine administered to an individual child’. A daily medicines log book is currently used which details the dosage given to a child. This form may seem long-winded for conditions that require regular medication and also duplicates existing paperwork.

Form 5: As above.

Form 6: ‘Request for child to carry his/her own medicine’. Would this form be completed for older/secondary school children? It is not clear which age group the form should be used for.

Form 7: ‘Staff training record – administration of medicines’. Will this form replace the existing sign off sheets that healthcare professionals complete with schools? The form currently has space for only one trained staff member, which would not be adequate (usually two or more staff members receive training).

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

We would hope/expect to see the use of plain language and clear explanations given in any document explaining legal provisions. As such, we suggest that the opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. We would also raise concerns that the second paragraph contains several exceptions that provide gaps for inaction in multi-agency working.

Additionally, we would raise concerns that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is likely that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions. For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Gethin Jones

Organisation (if applicable): Royal College of Paediatrics and Child Health

email / telephone number: Gethin.jones@rcpch.ac.uk

Your address: RCPCH, Baltic House, Mount Stuart Square, Cardiff Bay CF10 5FH

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☒
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	x ☐

Supporting comments

The importance of high-quality healthcare for children and young people in the community and the importance of all educational settings being well equipped to manage children and young people with medical needs is set out the *Why Children Die (RCPCH, 2014* *http://www.rcpch.ac.uk/sites/default/files/page/Death%20in%20Children%20and%20Young%20People%20in%20the%20UK%20-%20Part%20C%20-%20ENGLISH%20WEB.pdf).* Children, young people and their families must be confident that they will receive the safest possible care and that they will be supported appropriately in the community to manage any ongoing conditions.

Whilst we welcome the Welsh Government's intention to improve and update the current guidance document, we are disappointed that the new guidance does not move away from the current voluntary framework and introduce a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must (not should) make additional arrangements for supporting pupils at schools with medical conditions.

We would have expected the revised Welsh guidance to have given consideration to whether a similar legislative duty for Welsh schools would improve care received by children and young people in schools. The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.
We believe that such measures are necessary to reduce adverse variability in provision of care and to standardise policies and procedures for schools as much as possible

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce. There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs. The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. We recommend that Welsh Government explores the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children and young people with medical needs.

The RCPCH (working together with the Royal College of General Practitioners, the Royal College of Nursing, the Royal College of Physicians and the Royal College of Psychiatrists) is developing new key standards (as part of its Facing the Future series) to reduce variations in care and improve the health outcomes and quality of life for infants, children and young people with long-term conditions. The standards are due to be published in November 2016. Please see the project webpage for further information: http://www.rcpch.ac.uk/improving-child-health/better-nhs-children/service-standards-and-planning/facing-future-long-term-c

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	**x** ☐	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document. The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales.

We feel that there has been a lack of engagement with children and families of children with medical needs. The stakeholder groups have engaged parents but not children and young people themselves.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We welcome the more concise nature of the new draft guidance.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	**x** ☐	**Neither agree nor disagree**	☐

Supporting comments

As the most common chronic disease of childhood with links to missed days from school and obesity, we would again call for mandatory rather than voluntary provision.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x** ☐

Supporting comments

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x** ☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

22

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: **Tristan Humphreys (Lead in Wales)**

Organisation (if applicable): **Coeliac UK**

email / telephone number:
Tristan.humphreys@coeliac.org.uk/

02920499732

Your address:
Room 5B,
Baltic House,
Mount Stuart Square,
Cardiff.
CF10 5FH

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

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	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐

	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☒
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

No. We believe the revised draft remains overly ambiguous and fails to provide adequate, concise direction to enable practitioners and organisations to better support children with medical needs.

As laid out below, we believe there are four key areas where the guidance could be improved; Clarity of tone and language, Nature of the duty, Important omissions & timescale and delivery in practice.

13. Clarity of tone and language

The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales.

The guidance gives the impression of having an institutional focus rather than being child-centred and contains numerous qualifiers and caveats rather than presenting, through the prism of children's rights, a clear set of roles and responsibilities. For instance it is noted that parents were not included as part of the initial review of the guidance and parents and learners are referenced after Local Authorities, Governing Bodies, Head teachers and teachers/support staff in Section 2.

Further to this, where parental/child engagement is championed in principle, it is often undermined in practice. On the one hand guidance suggests that “parents and learners should be active partners” (Section 2. P.12) and that it is unacceptable practice to “ignore the views of the learner or their parents/carers; or ignore healthcare evidence or opinion” (Section 4.p 26). Yet the guidance lays out clearly that in the case of Individual Health Care Plans “if consensus cannot be reached, the head teacher should take the final decision” (Section 3. P. 22). It is difficult to see how this is of help in the case of schools already failing to engage.

14. Nature of the duty – statutory or non-statutory?

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, resulting in the potential for discrimination which in turn may put them at risk of both academic and health disadvantage.

The introduction of a statutory duty of care for children with medical needs would bring Wales into parity with the English legislative system. In England, the Children and Families Act 2014 [2]came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** (not should) make additional arrangements for supporting pupils at schools with medical conditions. Central to this framework is the provision that **all** children with medical needs receive an Individual Healthcare Plan (IHP). We are particularly concerned that draft guidance explicitly makes clear that ‘not all learners with healthcare needs require an IHP’ (Section 3. P. 22) and that ‘the head teacher should take the final decision’ (Ibid). Parents of children with medical needs are left with no recourse when a school’s leadership refuses to implement an IHP, even if it has been advised by health care providers and is supported by the parents themselves.

Variability in provision of care provided in schools is a profound issue. As a UK-wide organisation, it is much more difficult to provide assistance and guidance to families and learners in Wales, where there is no explicit duty on schools which covers medical needs.

There are many examples of schools that simply ignore the current guidance, schools that deliver unsafe practice and of disengaged staff who will not collaborate with parents to rectify poor practice (*Report: Type 1 Diabetes in Schools in Wales - Diabetes UK, 2016)*. If the new guidance framework does not state precisely what schools **must** do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by schools. Children will be disadvantaged and parents will continue to be frustrated by Welsh Government guidance that is insufficiently specific or directive where their child is not being supported and may therefore be left vulnerable. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties.

We fail to see how the proposed guidance makes any clearer what measures are required to be put in place in order to adequately support learners with

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healthcare needs and with whom the responsibility lies to ensure such measures are implemented.

15. Important omissions and timescale

Practical omissions

We strongly urge Welsh Government to revise the draft guidance document to include practical advice with regard to dietary management as it is specifically relevant to children with coeliac disease and other medical conditions. In particular we are concerned that there is little to no reference to the importance of food management as a crucial facet of support for many children with medical needs both in the context of emergency and non-emergency chronic conditions. This applies not just in terms of ensuring inclusive and safe meal times but also in other contexts such as cookery lessons or schools trips. A child should not be prevented from accessing a safe hot meal or taking part fully in school activities because of any perceived inconvenience caused by their requirement for gluten free food.

As the national charity for Coeliac disease (a lifelong autoimmune condition effecting 1 in 100 people) we would also ask that you include us in the useful contacts section of this guidance.

We would also like to emphasise again the need for every child with medical needs to have in place an Individual Health Plan (IHP). The current draft is inadequate in this respect.

Timescale

Furthermore, we would like to raise our concern regarding the proposed June 2016 deadline for completion of the document. We feel that there has been a lack of consultation with stakeholders around this issue, including the engagement of children and families of children with medical needs. As a third sector organisation working closely on the issue of medical needs in school, we were surprised that we were not notified of the consultation's launch. The lack of communication regarding this consultation means that we now have a short time period to provide a full response and there is an increased risk that Welsh Government will not receive as wide a response to this consultation as is merited.

We would be very happy to attend a meeting with Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance document.

16. Delivery in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by the workforce.

We therefore recommend that Welsh Government explores the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The listed legislation does not relate specifically to medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These duties are not related to learners with healthcare needs".

The below examples are **some** of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.
- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22.
- Throughout the draft, there is an inconsistent use of bold/non-bold text with regards to duties and/or suggestions. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing "must" duties as well as "should" suggestions. This occurs throughout the document.
- The existing suggestions of good practice have not changed since the

2010 guidance. As stated on page 3, these suggestions “may be required or desirable”. If this is the case, we would query the need to highlight them in bold in 2016 and would raise concerns over what schools are currently doing if this needs to be highlighted 5 years after the guidance’ original implementation.

- Further optional clauses are evident throughout the document i.e. “IHPs can help” on page 22, “whether to prepare an IHP”. The draft also contains ‘If’ clauses, such as ‘If a policy is in place, it should be followed’ – does this mean this is optional?
- Interchangeable language and terminology is used throughout when referring to “statutory guidance” and “legal requirements”.
- Page 23 begins mid-sentence.
- Annex 2 ‘Useful Contacts’ section contains no contact information and is not in alphabetical order.
- There are errors in document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term ‘staff’ consistently throughout document i.e. page 11 ‘staff should be clear when a risk assessment is required’ with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on ‘other learners’ in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to ‘all necessary forms’ throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the concise nature of the new draft guidance but would raise concerns over the structure of the content/sections.

We recommend a common-sense approach to the list of contents and would advise further consultation with those who might use the document.

The guidance document applicable to England, ‘Supporting pupils at school with medical conditions’ contains the following sections in a clear and concise manner:

(xxv) The production, adherence and review of a school’s key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(xxvi) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(xxvii) Procedures for day trips, residential visits and sporting activities.
(xxviii) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(xxix) Staff training and support.
(xxx) Unacceptable practice, liability and indemnity issues and complaints.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We recommend providing a template IHP as part of Annex 3. An example can be found under 'England' on our schools guidance page here - https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/school-meals/

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

We would expect to see the use of plain language and clear explanations given in any document explaining legal provisions and as such, the opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. We are also concerned that the second paragraph contains several exceptions and qualifiers that could foster inaction and limit multi-agency working.

Additionally, we note that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. It is difficult therefore to see how this list provides any help in resolving common practical issues that are regularly experienced by children and families of children with medical conditions

For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Yet medical conditions or needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues for the precisely the group this guidance is supposed to support.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Coeliac Disease

Coeliac disease is a lifelong auto-immune disease, affecting around 1 in 100 people (c.30,000 in Wales). It is caused by the immune system reacting to gluten and can lead to a range of symptoms including bloating, diarrhoea, nausea, wind, constipation, anaemia, severe mouth ulcers and even hair loss. The only treatment is a strict, lifelong gluten free diet.

Impact on children

Eating gluten causes damage to the lining of the gut and results in malabsorption of nutrients from food and associated nutritional deficiencies. Symptoms specific to children include failure to thrive, diarrhoea, muscle wasting, poor appetite and lethargy. Strict adherence to the gluten-free diet is essential. Non adherence to the diet results in the reappearance of symptoms which can lead to absence from school that will ultimately impact on learning.

- *Failure to abide by a strict gluten-free diet can lead to significant complications such as osteoporosis and in rare cases small bowel cancer. It can also lead to recurrent ill health and poor attendance, resulting in a learner falling behind in the curriculum.*

What is gluten?

Gluten is a protein in the grains wheat, barley and rye. Some people with coeliac disease may also be sensitive to oats. Gluten is commonly found in foods such as bread, breakfast cereals, biscuits, pasta and cakes but it is also in foods that you may not expect, such as some sauces, ready meals and sausages. The gluten-free diet is the complete medical treatment for coeliac disease and it is essential that children with Coeliac Disease exclude all sources of gluten from their diet.

- *Coeliac UK's Gluten-free Checklist, available on the Coeliac UK website, is a guide to the types of foods that can be eaten, those that* *can't and those that need to be checked*.

Coeliac UK

Coeliac UK is the national charity for people with coeliac disease and dermatitis herpetiformis (DH), the skin manifestation of coeliac disease, giving support on healthcare and the gluten-free diet. We campaign, research and offer support and advice to people with these conditions and those supporting them. We have over 60,000 Members across the UK and more than 3,000 in Wales.

- Coeliac UK is the national charity for people with coeliac disease – www.coeliac.org.uk

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

23

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Sian Evans and Viv Jones

Organisation (if applicable):

email / telephone number: 02920 744294
Sian.evans13@wales.nhs.uk
viv.jones2@wales.nhs.uk

Your address: Paediatric Dieticians, University Hospital of Wales, Cardiff

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
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	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
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	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	x ☐
	Other public sector organisations	☐
	Third sector organisations	☐

	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x** ☐

Supporting comments

We feel the document is easy to understand and concise, but it isn't clear where parents can go if having problems with a school not meeting their health care needs. It takes a lot of coordination between parents, schools, healthcare professionals and catering staff to ensure dietary needs are met e.g in coeliac disease (gluten free), food allergies (avoiding food allergens).

There is no mention of food management. This is essential for children with conditions such as coeliac disease needing a STRICT gluten free diet, or children with severe food allergies.

It would be good to see Coeliac UK and CICRA (children with Crohns and Colitis) listed in the useful contacts section.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

From reading the guidance, it is not clear who is not responsible for what. E.g the draft mentions staff, without highlighting which staff are responsible for the child's needs.

It is not clear what the criteria are as to which children need an IHP (Individual Health Care Plan). We feel that as dietitians, there is no clarification in the document as to who is responsible for providing a suitable meal for the child. This could impair their inclusion in activities such as science and food technology lessons, compliance with their diet leading to healthcare problems, thus preventing children from participating in school life, e.g school meals.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**x** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor**	**x**

				disagree	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	**x** ☐	**Neither agree nor disagree**	**x** ☐

Supporting comments

Form 1: Contacting Emergency Services -

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

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<u>24</u>

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Elizabeth A. Atter MSc MCSP

Organisation (if applicable):

email / telephone number:liz.atter@ntlworld.com

Your address: 122, Pencisely Road, Llandaff, Cardiff.
CF51DR

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	X
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	X
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The use of BOLD font to highlight statutory guidance was helpful.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The flow chart on Page 8 is particularly clear and as suggested, could be printed and used as a poster in several different venues within the school buildings.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	**X**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Offering learners with healthcare needs the opportunity to 'have a voice' in their IHP and to be supported to self-manage their care is important in their transition from being 'the helpless sick child' to maturing into a responsible young person. It offers them a measure of control over their condition and teaches them to participate in their ongoing care into adult services within Education and Health

The inclusion and participation possibilities for learners in a more holistic way is refreshing in particular when considering cognitive, physical, emotional and behavioural status and looking at 'Education' in its broadest sense i.e. socially, sporting, educational and off-site activities.

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Dear Sir/Madam

The revised document concerning children with healthcare needs, appears to guide the local authority and teachers in how best to attend to children with healthcare needs and whom are of a compulsory school age.

My question: Is there a document guiding parents and carers of these needy children in how to obtain help from the local authority, specifically which routes to take.

There appears to be a considerable amount of guidance for the authorities and teachers, but for a parent trying to gain the help of these governing bodies, there seems to be no help or guidance whatsoever. My special needs child has not gone to preschool or nursery due to their affliction and because of this, we appear to be completely isolated from any governing assistance. We have tried getting help from the local authority, but seem to be going in circles and achieving nothing.

As a parent, can I use this revised document to try and get some help? Does this document entitle me and my child to a specific service from the council? Can we use this document to hold the council responsible should they fail to provide us with any assistance (which is currently the case)?

I realise you may not be able to answer my questions or address my concerns, but if you could please direct me to someone who can help, that will be most appreciated.

Yours Sincerely

Vanessa Gwenin
Senior research Officer
ARCH group
School of Chemistry
Bangor University

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Cefnogi dysgwyr ag anghenion gofal iechyd

Ffurflen ymateb i'r ymgynghoriad

Eich enw: Ywain Myfyr

Sefydliad Undeb Cenedlaethol Athrawon Cymru:

e-bost / rhif ffôn: 01970639950

Eich cyfeiriad: UCAC, Ffordd Penglais, Aberystwyth, Ceredigion SY23 2AZ

Dylid dychwelyd ymatebion erbyn **29 Ebrill 2016** i:

Y Gangen Anghenion Dysgu Ychwanegol
Yr Is-adran Cymorth i Ddysgwyr
Yr Adran Addysg a Sgiliau
Llywodraeth Cymru
Parc Cathays
Caerdydd
CF10 3NQ

Neu gellir cwblhau'r ffurflen yn electronig a'i hanfon i'r cyfeiriad isod:

e-bost: additionallearningneedsbranch@cymru.gsi.gov.uk

Categori'r ymatebwyr	Ysgolion	☐
	Ysgolion arbennig	☐
	Cydlynwyr Anghenion Addysgol Arbennig	☐
	Y sector addysg bellach	☐
	Sefydliadau cyn ysgol	☐
	Gweithwyr proffesiynol ym maes addysg	☐
	Undebau athrawon	☒
	Llywodraeth leol	☐
	Sefydliadau dysgu seiliedig ar waith	☐
	Byrddau Iechyd Lleol	☐
	Gweithwyr iechyd proffesiynol	☐
	Sefydliadau eraill o'r sector cyhoeddus	☐
	Sefydliadau'r trydydd sector	☐
	Unigolion	☐
	Arall	☐

Cwestiynau ymgynghori

Dylai'r cwestiynau hyn gael eu darllen ar y cyd â'r drafft Cefnogi Dysgwyr â Gofal Iechyd dogfen gyfarwyddyd , sy'n disodli'r Mynediad i Addysg a Chymorth i Blant a Phobl Ifanc ag Anghenion ddogfen gyfarwyddyd Anghenion Meddygol. Dylid Cwestiwn 4 gael ei darllen ar y cyd â'r Canllawiau ar ddefnyddio anadlyddion salbutamol brys mewn ysgolion yng Nghymru dogfen (2014) .

Cwestiwn 1 – Cynnwys y ddogfen canllawiau diwygiedig

A ydych yn cytuno bod y drafft diwygiedig Cefnogi Dysgwyr ag Anghenion Gofal Iechyd dogfen gyfarwyddyd yn glir ac yn hawdd i'w deall?

Cytuno	☐	**Anghytuno**	☐	**Ddim yn cytuno nac yn anghytuno**	☒

Sylwadau ategol

At ei gilydd cytunwn fod y ddogfen Cefnogi Dysgwyr ag Anghenion gofal Iechyd yn glir ac yn hawdd eu deall.

Cwestiwn 2 – Fformat/ cyflwyniad y ddogfen canllawiau diwygiedig

A ydych yn cytuno bod y drafft diwygiedig Cefnogi Dysgwyr ag Anghenion Gofal Iechyd dogfen gyfarwyddyd yn glir yn ei chyflwyniad o ddyletswyddau cyfreithiol a chyngor i gyrff llywodraethu ac awdurdodau lleol? Mae hyn yn cynnwys cyflwyniad y cynnwys a fyddai'n cael eu cyhoeddi fel canllawiau statudol (mewn ffont trwm); gwybodaeth sy'n grynodeb o ddyletswyddau cyfreithiol; a chyngor cyffredinol.

Cytuno	☒	**Anghytuno**	☐	**Ddim yn cytuno nac yn anghytuno**	☐

Sylwadau ategol

Un peth ydy gosod gofynion a chyhoeddi canllawiau statudol, ond mae'n rhaid cael yr adnoddau a'r hyfforddiant i'w cefnogi. Profiad ein haelodau yw bod yr hyfforddiant yn brin a bod y cyfrifoldebau yn syrthio ar yr ysgol heb ddigon o gefnogeath oddi wrth bobl broffesiynol eraill efo'r honiad yn aml nad yw'r staff ar gael. Ymddengys fod cyfrifoldebau'r Corff Llywodraethol yn sylweddol, ond o brofiad bydd y cyfrifoldebau

yma yn disgyn ar y pennaeth ac yn ychwanegu at y llwyth gwaith sydd eisoes yn sylweddol.

Cwestiwn 3 – Strwythur y ddogfen canllawiau diwygiedig

A ydych yn cytuno bod y drafft diwygiedig Cefnogi Dysgwyr ag Anghenion Gofal Iechyd dogfen gyfarwyddyd wedi'i strwythuro'n glir? A ydych yn gallu dod o hyd i'r wybodaeth rydych ei angen yn hawdd neu eisiau gwybod drwy ddefnyddio'r ddogfen ganllawiau diwygiedig?

Cytuno	☐	**Anghytuno**	☐	**Ddim yn cytuno nac yn anghytuno**	☒

Sylwadau ategol

Byddai cael templed o bolisi(au) a samplau o Gynlluniau Gofal Iechyd Unigol yn fuddiol.

Cwestiwn 4 –Canllawiau ar ddefnyddio anadlyddion salbutamol brys mewn ysgolion yn y ddogfen Cymru (2014)

A ydych yn cytuno bod yr Arweiniad ar y defnydd o ymanadlwyr salbutamol brys mewn ysgolion yn y ddogfen Cymru yn rhoi cyngor digonol i ysgolion a / neu awdurdodau lleol ar y newidiadau i reoliadau DU caniatáu i ysgolion i gynnal anadlyddion salbutamol argyfwng?

Cytuno	☐	**Anghytuno**	☐	**Ddim yn cytuno nac yn anghytuno**	☒

Sylwadau ategol

Mae'r canllawiau yn glir ac i'w croesawu, serch hynny mae gennym ychydig o bryderon gan y gall ychwanegu at lwyth gwaith ysgolion. Nodir y dylai ysgolion wirio oedran ymanadlwyr a meddyginiaethau, credwn y dylai'r cyfrifoldeb yma fod ar y rhieni/gwarchodwyr ac ni ddylid disgwyl i ysgolion wirio dyddiadau'r meddyginiaethau yma.

Byddai templed o bolisi a pro forma archebu anadlyddion brys yn fuddiol i leihau dyblygu gwaith.

Cwestiwn 5 – Ffurflenni ychwanegol ar gyfer y Dysgwyr Cynorthwyo ag Anghenion Gofal Iechyd

A ydych yn cytuno bod gan dogfennaeth ategol sydd ar wahân (Atodiad 3) a ddarparwyd gyda'r dogfen Dysgwyr Cefnogi Gofal Iechyd gyda Anghenion yn ddigonol ar gyfer eich anghenion? Os ydych yn anghytuno, defnyddiwch y blwch isod i awgrymu unrhyw ychwanegiadau posibl neu newidiadau i'r deunyddiau hyn.

Cytuno	☐	**Anghytuno**	☐	**Ddim yn cytuno nac yn anghytuno**	☒

Sylwadau ategol

Rydym yn croesawu unrhwy gyhoeddiad o ofoynion sy'n cynnwys sampl o'r ffurflenni i'w defnyddio. Rydym yn crosawu'r datganiad ar Furflen 2 mai gwrifoddol yw rhoi meddyginiaeth.

A fyddai angen llenwi Ffurflen 4 a 5?
Dylid nodi swydd yr hyfforddwr ar Ffurflen.
Byddai sampl o Asesiad Risg ar ddisgybl yn ddefnyddiol hefyd.

Cwestiwn 6 - Amlinelliad o'r fframwaith cyfreithiol

A yw'r atodiad fframwaith cyfreithiol (Atodiad 1) yn ddefnyddiol wrth dynnu sylw at y prif ddarpariaethau cyfreithiol sy'n gysylltiedig â diogelu lles plant ag anghenion gofal iechyd?

Cytuno	☐	**Anghytuno**	☐	**Ddim yn cytuno nac yn anghytuno**	☒

Sylwadau ategol

Cwestiwn 7: Os oes gennych unrhyw faterion neu sylwadau cysylltiedig yn ogystal â'r pwyntiau uchod defnyddiwch yr ofod hwn i roi gwybod iddyn nhw os gwelwch yn dda:

Os gwelwch yn dda nodwch yma:

- Pam fod angen sôn am yswiriant indemniad? Oni ddylai hynny fod ynghlwm wrth gyflogaeth staff ysgol beth bynnag?
- Mae hwn yn gyfrifoldeb ychwanegol ar Lywodraethwyr sydd yn gorfod ymdopi efo mwy a mwy o ddyletswyddau.
- Oes gan Awdrudodau Lleol y staff i gefniogi ysgolion ar y materion hyn bellach?
- Mae problemau yn codi pan fo staff sydd wedi eu hyfforddi i ddelio â disgybl penodol i ffwrdd o'r gwaith. Mewn gwrionedd mae angen hyfforddi cynifer â phosibl o staff ysgol i sicrahu darpariaeth ddigonol.
- Rhaid bod yn glir ynghylch cyfrifoldeb pennaeth pan nad yw ei staff yn fodlon rhoi meddyginiaeth
- Pwy o fewn ysgol ddylai fod â'r cyfrifoldeb dros lunio a monitro'r Cynllun Gofal Iechyd Unigol? A oes angen amser digyswllt?
- Yn anffodus teimlwn fod yn rhaid i ni dynnu sylw at safon gywilyddus y Gymraeg yn y ddogfen ymgynghorol (nid y canllawiau drafft). Mae'n amlwg iawn mai cyfieithu cyfrifiadurol sydd wedi'i wneud a heb gyfieithydd proffesiynol yn edrych drosto wedyn

Mae ymatebion i ymgynghoriadau yn debygol o gael eu gwneud yn gyhoeddus, ar y rhyngrwyd neu mewn adroddiad. Os byddai’n well gennych i’ch ymateb aros yn ddienw, ticiwch yma: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Mandy East

Organisation: Anaphylaxis Campaign

email / telephone number: mandy@anaphylaxis.org.uk

Your address: 1 Alexandra Road, Farnborough, GU14 6BU

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
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	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	X
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	X	**Neither agree nor disagree**	☐

Supporting comments

In general, we disagree with the proposed draft and find the content disappointing, as it fails to address both ‘learners’ and their ‘healthcare needs’ during the school day. The document appears to have been written very much from an education point of view and lacks clarity about the rights of a child with healthcare needs during the school day.

Tone & Language

The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales. The draft does not place children at the heart of the document, which should be the motivation for this policy area.

Where parental/child engagement is championed in principle, it is often undermined in practice. On the one hand guidance suggests that “parents and learners should be active partners” (Section 2. P.12) and that it is unacceptable practice to “ignore the views of the learner or their parents/carers; or ignore healthcare evidence or opinion” (Section 4.p 26). Yet the guidance lays out clearly that in the case of Individual Health Care Plans “if consensus cannot be reached, the head teacher should take the final decision”. It is difficult to see how this is of help in the case of schools already failing to engage. Indeed we find no clear evidence from the document that learners with healthcare needs have been consulted as part of the process in formation of this document. Since they are a major stakeholder, more effort could have been made to engage patient and parent groups.

Outcomes

Whilst we welcome the Welsh Government’s intention to improve and update the current guidance document for managing chronic diseases in schools, we would expect new guidance and its accompanying framework to adopt measures that will reduce adverse variability in provision of care and that will standardise policies and procedures for schools as much as possible in a move away from the current voluntary framework.

In reading the draft Supporting Learners with Healthcare Needs, there is a distinct lack of progression since the 2010 guidance in increasing or improving support for children with medical needs at school. We therefore believe that the proposed draft guidance will produce the same variable and inequitable outcomes in access to education that currently prevail across Wales.

Many schools across Wales deliver good care and support. The Welsh Government has the opportunity to fine-tune the care these schools provide, to learn from them and to share best practice so that all children receive equitable school care. The real challenge is how to improve support and care for schools that are disengaged and currently fail to deliver the right care.

In order to improve the existing framework, we recommend the following be put in place as a matter of urgency:

17. Nature of the duty: Statutory duty or Non-statutory duty?

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** (not should) make additional arrangements for supporting pupils at schools with medical conditions. Central to this is the provision that **all** children with medical needs receive an IHP. We are particularly concerned that draft guidance explicitly makes clear that ‘not all learner with healthcare needs require an IHP’ and that ‘the head teacher should take the final decision’. Parents of children with medical needs are left with no recourse when a school’s leadership refuses to implement and IHP, even if it has been advised by health care providers and the parents themselves.

Previous guidance in Wales has failed because of ambiguity across multiple demonstrable areas. Evidence shows that it’s voluntary, non-directive approach means that it is ignored by a number of disengaged schools because it was insufficiently directive, lacked clarity of roles and failed to set out basic requirements in delivering effective support. The new guidance will fail if this is not addressed. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties. Variability in provision of care provided in schools is a profound issue. As a UK-wide organisation, it is much more difficult to provide assistance and guidance to supporters in Wales, where there is no explicit duty on schools which covers medical needs.

Contact with families demonstrates that even when parents articulate their concerns to schools, some are unwilling to change practices to improve support systems. This leads to poor care for children and dangerous situations where procedures and safety systems are not followed. These children are at a disadvantage and are likely to achieve worse health outcomes at an increased cost to them and to the NHS. Parents will continue to be frustrated by Welsh Government guidance that is insufficiently specific and directive in assisting them in meetings with schools where they have genuine concerns that their child is not safe and is not being supported. The impact on families is significant, with both children and parents lacking confidence that the right care and expertise is in place.

If the new guidance framework does not state precisely what schools **must** do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by a number of schools. We fail to see how the proposed guidance makes any clearer what measures are required to be put in place in order to adequately support learners with healthcare needs and with whom the responsibility lies to ensure such measures are implemented.

18. The ability to deliver in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce.

There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs. Schools regularly articulate their concerns regarding their legal position in caring for children with diabetes and view the lines of responsibility as unclear with the current voluntary system.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. How do we reconcile voluntary roles with the provision of effective support for a child with complex medical needs when away from home? The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises and where this is not viable, put a child’s health and education at risk.

Evidence from families and schools indicates that there are not enough trained adults to provide an adequate level of care for children with medical needs in a school setting, despite the high level of support provided by NHS staff. Many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care. The training of supply teachers also presents difficulties.

We therefore recommend that Welsh Government explores the implementation of any new guidance with the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs. In some circumstances, this could be achieved by a new directional role of the school nurse.

19. Practical omissions

We strongly urge Welsh Government to revise the draft guidance document to include practical advice with regard to food management and school transport that relates specifically to children with medical needs. In particular we are concerned that there is little to no reference to the importance of food management as an important facet of support for many children with medical needs, both in the context of emergency and non-emergency chronic conditions.

We would also like to emphasise the need for every child with medical needs to have in place and Individual Health Plan (IHP). The current draft is inadequate in this respect.

Timeline

Furthermore, we would like to raise our concern regarding the proposed June 2016 deadline for completion of the document. We feel that there has been a lack of consultation with stakeholders around this issue, including the engagement of children and families of children with medical needs. As a third sector organisation listed throughout the consultation and draft documentation, we were surprised that we were not notified of the launch of the consultation. The lack of communication regarding this consultation means that we now have a short time period for responses and there is an increased risk that Welsh Government will not receive as wide a response to this consultation as is merited.

We would be very happy to attend a meeting with Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance document.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	X	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The use of 'bold' font to imply information which has a legal duty is poor and does not focus the reader to the purpose of the document. It tends to suggest that anything not in bold is unimportant, which clearly is not the case. We would suggest removing the 'bold' font and replacing this with clear bullet pointed recommendation tables.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These duties are not related to learners with healthcare needs".

The below examples are some of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.
- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22.
- Throughout the draft, the inconsistent use of bold/non-bold text with regards to duties and/or suggestions is confusing. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing "must" duties as well as "should" suggestions. This occurs throughout the document.
- The existing suggestions of good practice have not changed since the 2010 guidance. As stated on page 3, these suggestions "may be required or desirable". If this is the case, we would query the need to highlight them in bold in 2016 and would raise concerns over current schools practice if Welsh Government feels that this needs to be highlighted 5 years after the guidance was originally implementation.

- Further optional clauses are evident throughout the document i.e. “IHPs can help” on page 22, “whether to prepare an IHP”. The draft also contains ‘If’ clauses, such as ‘If a policy is in place, it should be followed’ – does this mean this is optional?
- Interchangeable language and terminology is used throughout when referring to “statutory guidance” and “legal requirements”.
- Page 23 begins mid-sentence.
- Annex 2 ‘Useful Contacts’ section contains no contact information and is not in alphabetical order.
- There are dangerous errors in the document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term ‘staff’ consistently throughout document i.e. page 11 ‘staff should be clear when a risk assessment is required’ with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on ‘other learners’ in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to ‘all necessary forms’ throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	X	**Neither agree nor disagree**	☐

Supporting comments

We welcome the more concise nature of the new draft guidance compared with the 2010 document but would raise concerns over the structure of the content/sections.

We would encourage a common-sense approach to the list of contents and would advise further consultation of those who might use the document. Many of the third sector patient support groups, who have a wealth of experience in producing parent/carer versions of guidance, would welcome the opportunity to be involved in this initiative.

The guidance document applicable to England, ‘Supporting pupils at school with medical conditions’ contains the following sections in a clear and concise manner:

(xxxi) The production, adherence and review of a school’s key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(xxxii) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(xxxiii) Procedures for day trips, residential visits and sporting activities.
(xxxiv) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(xxxv) Staff training and support.
(xxxvi) Unacceptable practice, liability and indemnity issues and complaints.

The current draft is not written in a format suitable for parents and carers and consideration should be given to produce a more easy-to-read version of the document.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We welcome the changes which allow schools to hold and emergency salbutamol inhaler and hope this is being taken up across Wales. We would like to query one area of the guidance and that is on page 8 which outlines asthma attack procedure. Bullet point three on this page tells staff to “check consent in the asthma register” and we are concerned that this could delay emergency treatment during an attack**.**

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x**

Supporting comments

It is unclear which document Annex 3 is, as there is no such entitled document. In the absence of this, we will provide feedback on the document entitled ‘Forms’:

Form 1: ‘Contacting Emergency Services’. The information on page 2 directly contradicts the guidance document. Page 2 advises staff to contact 99 in an emergency, whereas the guidance document signposts staff to NHS Direct.

Form 2: ‘Parental agreement for school/setting to administer medicine’. This form may not be suitable for every condition and is very similar to an Individual Health Plan and so would be a duplication of paperwork. It may also be appropriate to include more than one contact details for family members.

Form 3:

Form 4: ‘Record of medicine administered to an individual child’. A daily medicines log book is currently used which details the dosage given to a child. This form may seem long-winded for conditions that require regular medication and also duplicates existing paperwork.

Form 5: As above.

Form 6: ‘Request for child to carry his/her own medicine’. Would this form be completed for older/secondary school children? It is not clear which age group the form should be used for.

Form 7: ‘Staff training record – administration of medicines’. Will this form replace the existing sign off sheets that healthcare professionals complete with schools? The form currently has space for only one trained staff member, which would not be adequate (usually two or more staff members receive training).

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	x	**Neither agree nor disagree**	☐

Supporting comments

We would hope/expect to see the use of plain language and clear explanations given in any document explaining legal provisions. As such, we suggest that the opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. We would also raise concerns that the second paragraph contains several exceptions that provide gaps for inaction in multi-agency working.

Additionally, we would raise concerns that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is likely that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions. For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

The Anaphylaxis Campaign receives numerous calls to our helpline from parents of school aged children who are struggling to get adequate care for their young people. Starting school (either for the first time, changing teachers or class or moving on to a new school) is an anxious time for both the young person and the family and teaching and school staff can ease this anxiety considerably. Learning how to care for and the day to day caring of a child with a health condition should be part of the schools' duty of care and we are proud to have been part of the working group which achieved this change in schools in England. We feel it is time for Wales to make the same amendments.

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Justin Warner

Organisation (if applicable):
Consultant Paediatric Diabetologist,
Diabetes UK Clinical Champion,
Clinical Lead for the National Paediatric Diabetes Audit,
Children's Hospital for Wales, Cardiff.

email / telephone number:
justin.warner@wales.nhs.uk 02920746374
Your address:Dept of Child Health, Children's Hospital
for Wales, Heath Park, Cardiff CF14 4XN

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	x
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	x ☐	**Neither agree nor disagree**	☐

Supporting comments

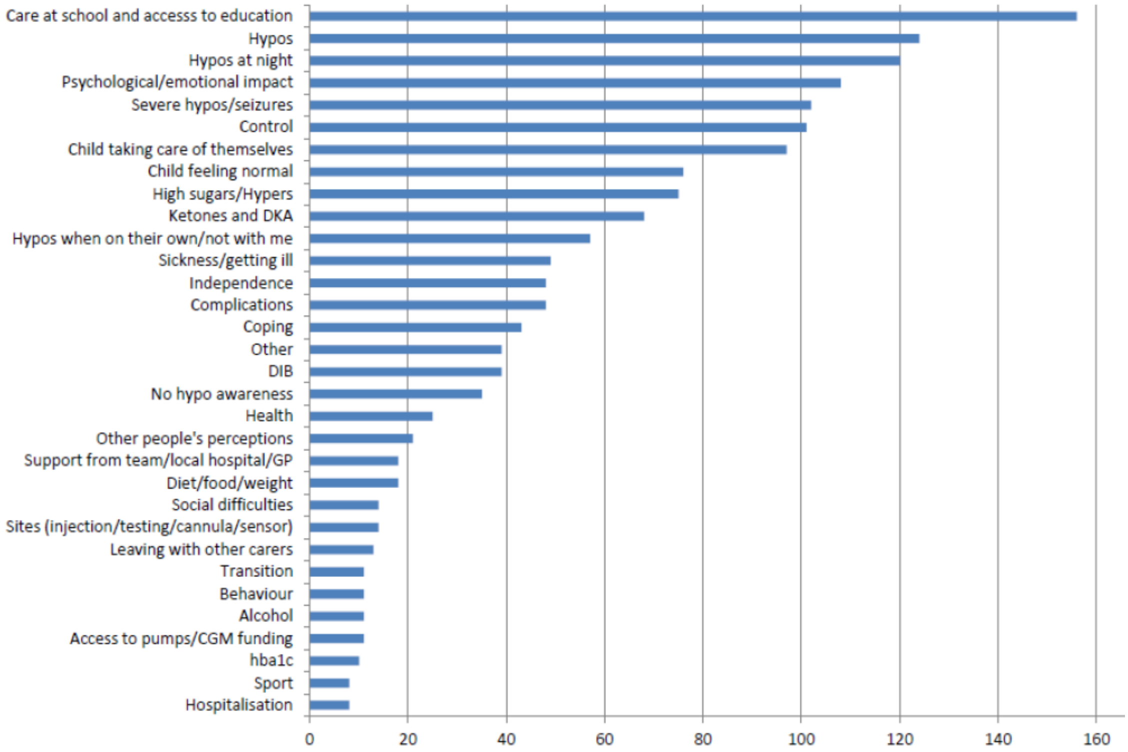
This new draft guidance document ‘Supporting learners with Healthcare Needs’ which updates the previous published guidance in 2010, is disappointing and does not provide children, parents or indeed schools with enough clarity about how to support and care for children with chronic healthcare needs during the school day.

I respond to this consultation document as a consultant paediatrician who provides care for 220 children and young people in Cardiff and the Vale of Glamorgan who have Type 1 diabetes. I have also been appointed as a Clinical Champion by Diabetes UK (the leading charity supporting people with diabetes) to work with them as a healthcare professional to improve the quality of care and reduce the inequality that is seen in support for children with diabetes during the school day. I am also the clinical lead for the National Paediatric Diabetes Audit for England and Wales where I have a major role in driving Quality Improvement for children’s diabetes services.

Managing Type 1 diabetes in children is complex. Unlike many other chronic health problems, it requires management, treatments and surveillance every moment of the day, seven days per week. Children with diabetes spend a major part of their life at school where good management is essential to achieve good diabetes control. This will have long lasting benefits as good control reduces the lifetime risk of morbidities such as blindness, kidney failure requiring dialysis and limb amputations. The latest research suggests that children with diabetes live 10-12 years less than the general population and gaining excellent control reduces risk and increases life expectancy. Therefore, we cannot ignore the time spent in school and teachers and carers during this time need appropriate training to provide them with the confidence to look after children with diabetes and other chronic health conditions.

As clinical lead of the largest children’s diabetes service in Wales my team interact regularly, often several times a week, with schools and so we believe we are uniquely placed to comment on how the medical needs of children should be met during school hours. We value the partnerships that we have built with school staff to ensure that children and young people with diabetes receive an excellent chance of living as normal a life as possible, which is one of the primary aims of the Welsh Government's Diabetes Delivery Plan (2013).

A recent survey by the Families with Diabetes National Network across England and Wales highlighted that the major concern that parents have about their child's care was during the school day. This concern cannot be ignored and parents need to have confidence in the people that will care for their child during the school day. The results of the survey are shown below. The question asked was 'what concerns you most about your child's diabetes care?'



My feeling is that the content of the draft guidance is unclear and has been written very much from an educational perspective rather than trying to build the guidance around the care of the child with the chronic disease. The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales. It also does not clearly set out the responsibilities for schools and staff working in education with regard to including children and young people with chronic illness, especially with reference to diabetes. It is so important that the child is not forgotten and should be at the forefront of any recommendations made in the document.

The document appears to focus on protecting schools and LEAs rather than safeguarding and promoting children's health and educational rights and needs. It explicitly protects school staff from having to take responsibility for a child's medical care, which I feel indicates a bias to the professional and does not place children's health at the heart of the document, which should be the motivation for this policy area.

There is a lack of statutory protection for the rights of children and young people with chronic illnesses like diabetes to equal access to education. In England the law has been changed to guarantee the rights of children with medical needs whilst they are at school. The Children and Families Act (England only) 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must (not should) make additional arrangements for supporting pupils at schools with medical conditions. Surely this legislation should be adopted in Wales as well. It seems unfair that children in Wales do not have the same protection or guarantees. It begs one to question whether the Welsh Government feel the medical needs of children in Wales are less important than the needs of children in England.

Whilst the implementation of the legislation in England is in its infancy, nevertheless there are early indicators of an increase in school engagement with medical conditions. Diabetes UK, who I work closely with in my clinical champion role, have seen a marked increase in the number of healthcare professionals who are nominating a school for the Diabetes UK 'Good Care in Schools Award', and comparative evidence gathered annually by the charity shows improved parent experience of working together with schools. Anecdotally, speaking to my England counterparts, the new legislation has allowed this to happen by putting a mandate on schools to interact with health in a more positive manner.

Indicator	2013	2014	2015
Percentage of parents who are satisfied with the diabetes care provided to their child at school	67%	71%	72%
Percentage of parents who state that an individualised care plan is in place which meets their child's needs.	51%	66%	85%
Proportion of schools that have access to Type 1 diabetes training.	66%	66%	73%
Proportion of schools with appropriate policies and procedures in place to provide children with Type 1 diabetes with consistent, individualised care (including IHP that covers extracurricular activity)	7%	58%	71%

The Cardiff and Vale University Health Board have recognised the need for an enhanced schools educator role for children's diabetes and have appointed the first person to this post in March 2016, the only Health Board in Wales to date to do this.

Clarity of information provided in the document is key to success. The 2010 guidance failed because of ambiguity across multiple demonstrable areas. Evidence shows that a small number of disengaged schools ignore previous guidance because it was insufficiently directive and lacked clarity of roles, requirements and how to deliver effective support. The new guidance will fail if this lack of clarity is not addressed.

Contact with families demonstrates that some schools ignore the current guidance framework, are disengaged, and even when parents articulate concerns, are unwilling to change practice or improve support systems. I have also provided along with this response to the consultation a report written by myself, the Children and Young Peoples Wales Diabetes Network and Diabetes UK, entitled 'Type 1 diabetes in Schools in Wales "An excellent chance", which provides evidence from families and healthcare professional where schools are letting children with diabetes down. The current guidance framework has failed for these schools. It's voluntary, non-directive approach means that it is ignored.

There are, of course, many examples of schools across Wales that deliver excellent care and support. This new guidance now has the opportunity to build on this and provide a pathway for schools that are disengaged and currently fail to deliver the recommended care.

If the new guidance framework does not state precisely what schools **must** do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by this small number of schools. Children at these schools will be disadvantaged and parents will continue to be frustrated by Welsh Government guidance that is insufficiently specific or directive to assist them in meetings with schools where they have genuine concerns that their child is not being supported and is not safe. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties.

To improve the existing framework, I would recommend the following actions as a matter of urgency although I actually believe the current document needs a new approach and requires more stakeholder involvement at a planning stage rather than at this very late consultation phase:

20. Statutory duty

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

Will the Welsh Government continue to allow this to happen?

There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. As stated already, in England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** (not should) make additional arrangements for supporting pupils at schools with medical conditions.

21. The ability to deliver in practice

Whilst I think it correct to introduce a statutory duty, I realise that this cannot work in isolation and needs to be supported by an adequate workforce. This requires a collaborative approach between health and education.

There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs. Schools regularly articulate their concerns regarding their legal position in caring for children with diabetes and view the lines of responsibility as unclear with the current voluntary system.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises and where this is not viable, put a child's health at risk. I would welcome the inclusion of healthcare professionals from local health boards, in the list of stakeholders with responsibilities. The current reference to School Nurses in the document ignores the fact that School Nurses are rarely involved with the treatment of diabetes at school. Training is carried out by healthcare professionals, usually diabetes nurses, employed by local health boards. This could be recognised in the guidance with schools and parents encouraged to work in partnership with their local paediatric diabetes teams. School nurses rarely have the specialist knowledge and training to provide advice to teachers and school staff about diabetes management.

Evidence from families and schools indicates that there are not enough trained adults to provide an adequate level of care for children with medical needs in a school setting, despite the high level of support provided by NHS staff. Many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care. The training of supply teachers also presents difficulties.

I would recommend that Welsh Government explores the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs. An example of this is being piloted in Cardiff & Vale University Health Board with a qualified nurse working as a 'School's Educator' to train and advise school staff with regards to diabetes care. This model could be included in the guidance as a recommendation for LEAs across Wales.

22. Practical omissions

I would also urge revision of the draft guidance document to include practical advice such as food management, school transport and the need for **every** child with medical needs to have in place and Individual Health Plan (IHP). The current draft is inadequate.

I have already had two meetings with the SCMO for Woman's and Child Health (Heather Payne) about issues around diabetes and school would be very happy to attend a meeting with Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance document.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	x ☐	**Neither agree nor disagree**	☐

Supporting comments

I find the bold and not bold use of text inconsistent and confusing. As stated in the previous section there is a great need for this guidance to **all** become statutory and that would negate the need for the bold text. The current use of this format tends to suggest bold important and non-bold not important which should not be true. Furthermore, it does provide clear recommendations that support the child with a chronic disease in the day to day school environment or at specific highlighted times such as school trips etc.

I welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These duties are not related to learners with healthcare needs.......".

The below examples are **some** of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity (you will find other responders to this document with similar examples as I have worked with others in formulating this response):

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.

- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22. I do not agree that the final decision on whether to develop an IHP should reside with the head teacher as this is a healthcare issue. I would expect every child with a healthcare need to have an IHP.
- Throughout the draft, there is an inconsistent use of bold/non-bold text with regards to duties and/or suggestions as already mentioned. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing "must" duties as well as "should" suggestions. This occurs throughout the document.
- The existing suggestions of good practice have not changed since the 2010 guidance. As stated on page 3, these suggestions "may be required or desirable". If this is the case, I wonder why they are highlight in bold in 2016 and would raise concerns over what schools are currently doing if this needs to be highlighted 5 years after the guidance' original implementation.
- Further optional clauses are evident throughout the document i.e. "IHPs can help" on page 22, "whether to prepare an IHP". The draft also contains 'If' clauses, such as 'If a policy is in place, it should be followed'. Policies should not be optional.
- Interchangeable language and terminology is used throughout when referring to "statutory guidance" and "legal requirements".
- Page 23 begins mid-sentence.
- Annex 2 'Useful Contacts' section contains no contact information and is not in alphabetical order.
- There are errors in the document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term 'staff' consistently throughout document i.e. page 11 'staff should be clear when a risk assessment is required' with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on 'other learners' in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to 'all necessary forms' throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☐ x	**Neither agree nor disagree**	☐

Supporting comments

I very much agree with making the document as concise as possible with use of appendices where possible. However, I do have concerns over the structure of the content/sections. There needs to be a common-sense approach to the list of contents with possible consultation from those who might use the document. An option to produce a lay person document should be seriously considered for parents who find it difficult to navigate around the legal jargon.

The guidance document applicable to England, 'Supporting pupils at school with medical conditions' contains the following sections in a clear and concise manner:

(xxxvii) The production, adherence and review of a school's key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(xxxviii) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(xxxix) Procedures for day trips, residential visits and sporting activities.
(xl) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(xli) Staff training and support.
(xlii) Unacceptable practice, liability and indemnity issues and complaints.

Although the list of unacceptable practices on page 26 is good, it needs more clarity to make clear that it is unacceptable to allow any of these scenarios to occur. Currently the wording is woolly and there is no firm commitment to ensure these examples of discrimination are prevented. In its current form I would question whether, without statutory and mandatory underpinning these unacceptable practices, they would be prevented. The list could be reversed as a series of positive statements e.g. ‘We aim for all learners with healthcare needs to attend mainstream education, unless this would cause harm to the learner’. This list could then lead the document as a sequence of aspirations which all schools in Wales should seek to meet.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	x ☐

Supporting comments

I have not covered this section as I’m responding on behalf of children with diabetes. However, why has salbutomol been highlighted. What about other medications required in school.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	x ☐

Supporting comments

These forms are helpful but many of these already exist and need to be adapted for the specific healthcare problem. It needs to be made clear that any documentation needs to be completed as a joint process between the school teacher, parent/carer and healthcare professional representing the particular medical problem.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x**

Supporting comments

This section needs the use of plain language and clear explanations given when explaining legal provisions. The opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. Furthermore, the second paragraph contains several exceptions that provide gaps for inaction in multi-agency working.

The listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is possible that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions.

For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

I would like to see the statutory and mandatory protection of the rights of school children in line to the protection given to children in England under the Families Act.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

I feel this document requires a rethink. It needs supporting by legislative change otherwise it will fail to be utilised similar to the previous 2010 document. I work very closely with Diabetes UK who have convened meetings with other charitable organisations providing advice to patients with healthcare needs about school. There is an overwhelming concern that this document does not support children in Wales in a similar manner to those in England. This needs prompt action.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form	Your name: Mary van den Heuvel Organisation (if applicable): ATL Cymru email / telephone number: mvandenheuvel@atl.org.uk; 02920 465 000 Your address: 9 Columbus Walk, Brigantine Place, Cardiff, CF10 4 BY

Responses should be returned by 29 April 2016 to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☒
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

About ATL Cymru – the education union

The Association of Teachers and Lecturers represents over 160,000 education professionals across the four constituent parts of the United Kingdom. It draws its membership from teachers and lecturers, leaders and support staff in maintained and independent schools, and Further Education Colleges. As well as campaigning vigorously to protect and enhance members' pay and conditions ATL also believes that the education profession has a key role in developing education strategy and policy. ATL Cymru represents over 6,500 education professionals in colleges and schools across the whole of Wales.

Our response

ATL Cymru welcomes the opportunity to respond to this consultation.

We are, however, deeply concerned that this work does not meet the expectations of those who have been working on the ALN draft code issued in 2015. We have included our comments on that code at the end of this document.

In terms of expectations of any code which relates to children with additional learning needs (ALN) and/or those learners with healthcare needs, we were expecting changes to include those up to 25. We recognise that the legal framework may not currently be there to make these changes, however, we would ask if there is a change in policy direction from Welsh Government, which promised to bring forward legislation on ALN?

If these changes in any way reflect a change in WG policy, which means that the code for both children with healthcare needs and those with ALN will be changed without changes to the legislation, we would be deeply concerned.

We would also emphasise that it is resources which are of primary importance to any of the ALN or healthcare needs provisions. Any bid to devolve responsibility to governing bodies risks undermining resources which may have been pooled at a local authority level.

Please see our comments on the draft ALN Code at the end of this document, as our concerns there, especially in relation to expectations of governing bodies and ALNCos also apply to this document.

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?					
Agree	☐	Disagree	☒	Neither agree nor	☐

				disagree	

Supporting comments

Whilst the guidance is clearly set out, the duties for different bodies named within the guidance is confusing.

Plans for the FE sector remain particularly unclear. Some ATL members are concerned that the draft plan mentions accommodating learners P/T if there are healthcare issues. Yet in FE the funding for 1 year courses does not always allow for completion over a longer period - the funding council needs to be aware that there are some learners who need to have some form of dispensation to study over a longer period owing to healthcare needs, for example learners with severe stress problems and ASD who find it difficult to maintain full attendance in any one week.

Some colleges have qualified staff to deal with access arrangements for exams but the length of study allowed for a particular course is reliant on the funding mechanism.

The guidance does not make explicitly clear enough the duty in the Equality Act 2010 on all service providers to make reasonable adjustments.

It also does not outline clearly the general and specific duties on public bodies in Wales under the Public Sector Equality Duty (section 149 Equality Act 2010). The guidance could include examples, or best practice case studies, of what adhering to the duties looks like for both schools and local authorities, as well as what they can expect from other bodies involved in education.

For example, a recent report of problems with the WJEC highlights some wider issues with understanding of the Equality Act duties: http://www.walesonline.co.uk/news/education/exam-board-told-visually-impaired-11223658

Question 2 – The format/presentation of the revised guidance document
Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	Disagree	☒	Neither agree nor disagree	☐

Supporting comments

The duties within this document seem to fall more heavily than before on Governing Bodies. We clearly set out in our response to the Draft Code on Additional Learning Needs why there are problems with this approach: https://www.atl.org.uk/Images/ATL_Cymru_response_to_draft_additional_learning_needs_and_education_tribunal_bill.pdf

There is no definition to define who children with healthcare needs are and therefore is difficult to see how this differs from the Additional Learning Needs Code of Practice which is due to be published soon.

The document uses bold print to highlight statutory duties, and yet many of these duties start with a ‘should’ rather than a ‘must’. More clarity about which body – LA/Governing body etc – is required to undertake the duties is needed to ensure the welfare and best learning outcomes for the learner.

Question 3 – The structure of the revised guidance document
Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	Disagree	☒	Neither agree nor disagree	☐

Supporting comments

The way in which the document is structured means that the emphasis is placed on what governing bodies should be doing rather than local authorities. The overarching duties on local authorities should be clear. If the duty remains with local authorities the expectations of their input should be at the beginning of this document to make it easier for everyone to understand.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)
Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	Disagree	☐	Neither agree nor	☒

				disagree	

Supporting comments

Whilst we agree that there are helpful elements to this guidance it is not clear where the duties and responsibilities lie.

Individuals should have any such responsibilities added to their job description and they should have the necessary training. For information on how what this guidance and support should include, please see our guidance: http://www.atl.org.uk/Images/ADV23%20Administering%20medicine%20-%20May%202012.pdf

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs
Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	Disagree	☐	Neither agree nor disagree	☒

Supporting comments

This template is helpful but should have more guidance associated with it.

Question 6 – Outline of the legal framework
Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	Disagree	☒	Neither agree nor disagree	☐

Supporting comments

The legal duties are not entirely clear. Whilst the 1996 Act appears to place the overarching duties on local authorities the way in which the document is structures implies that it is governing bodies who should be addressing the healthcare needs of the child as a pupil in their school.

We have commented above on the need for more clear guidance about the duty to make ‘reasonable adjustments’ contained within the Equality Act 2010.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Below is part of our response to the Draft Additional Learning Needs Code, which was consulted on at the end of 2015. We feel very strongly that any changes to ALN and children with healthcare needs should be done in conjunction with each other, and have very strong views about the proposals published in 2015. The summary of our views should be read alongside our comments on this consultation, especially those relating to governing bodies and extra duties placed on schools.

Our response

We welcome the opportunity to respond to this consultation. We are especially encouraged that the consultation is on the Bill in draft form. We believe this is the opportunity to address some serious issues with the draft bill, which is unworkable in its current form.

We have had a serious response from our members, who have expressed strong concerns about the draft Bill.

We remain fundamentally concerned about a draft Bill which has been described by the Education Minister on the 16th November 2015 as both ‘a radical and ambitious new system’[3] and “not radically different” for those who have additional learning needs. We therefore seek clarity on many issues which this draft creates, both for children and young people with ALN and the education professionals whom we represent.

Survey results

We undertook a survey of our members to inform our response[4]. The findings from the survey are included within our response as appropriate.

Respondents included those working in a range of settings – from class teachers to current ALNCos, headteachers to teaching assistants and those who manage specialist residential provision.

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[3] http://gov.wales/about/cabinet/cabinetstatements/2015/10705926/?lang=en

[4] Survey of ATL Cymru members ran from 3rd to 15th December 2015.

More than a third (37%) of those who responded to the question had management responsibilities. Their responsibilities ranged from one teaching assistant to 20 teaching staff and 92 non-teaching staff.

Our main concerns with the draft Bill are outlined below:

Funding

The funding arrangements for this draft Bill remain unclear. If the aim of this Bill is to save money then that must be made clear and explicit. If the Bill aims to improve the system, as implied, that will take resources. These resources have not been adequately identified. We would have grave concerns about the budget constraints which schools and FEIs can expect in relation to this Bill.

Indeed, we believe the main problem which underpins the current system is resources, rather than the structures in place. The draft Bill appears to create a system in which those with ‘severe and complex’ ALN will have a safeguard in terms of the local authority.

However, those with lower level additional learning needs (ALN) will have their additional learning provision (ALP) met by the school/ FEI etc. If there isn’t enough money currently in the system, or enough professionals like speech and language therapists and education psychologists, then simply passing the responsibilities onto governors and the costs onto school budgets will not work.

ALNCos

Nearly two thirds of those who answered our survey (58%) felt that the duties prescribed in the draft code for ALNCos are unworkable. ALNCos are extremely unlikely to be given the amount of training, time and support in order to achieve the requirements placed on them within the legislation. Many do not have extra pay for their extensive role either.

Comments from our survey suggest that the described list could work if it were for a whole ALN team in a large school or college, in which many were non-teaching staff. There were also concerns that senior leadership positions would be difficult to assign to ALN.

One member said:

“I would see this role as a full time position in itself. This list of responsibilities would be better taken on board by a designated ALN department that may be made up of several members of teaching staff.”

Another said:

“It’s a wish list, which may fully represent the challenges of the role but who would be able to fulfil this within the terms of employment? Recruitment and retention will be challenging. Many schools rotate the SENCO role without appropriate qualifications of the post holder”

Not all ALNCos are currently a member of the senior management team, and whilst this is welcomed in principle, it will take time and support from the school and governors. More than two thirds (68%) of our respondents said that they needed more time and support to undertake their ALN role.

We broke this down further within our survey, and found that half (49%) of respondents needed more time outside the classroom to undertake their ALN role to a standard they would like. 70% said they would like more training, whilst 34% said they would like more support from management.

Three quarters (73%) of our survey respondents said it would take more time to undertake the role as described in the draft Code.

Some people may face a restructure of the staff in their school and some will have to have more training to ensure they have the right qualifications. Nearly three quarters (71%) said they would like more training to undertake their ALN role to a standard they would like, whilst more than a quarter (27%) would like specific qualifications. A third (34%) would like more support from management.

We found some of our respondents were not a qualified teacher, member of the senior leadership team, experienced working with SEN/ALN children and young people or qualified specifically to work with SEN/ALN, but have the SENCo/ALNCo role. These people were working within the early years, primary and FEI settings.

More than three quarters (77%) of the current ALNCos who answered our survey said they had experience working with ALN children and young people, whilst only a third (33%) had specific qualifications.

As it stands, the ‘offer’ in terms of the ‘New Deal’ does not meet the needs for re-training required under the Code in this draft Bill.

Substantial monies will have to be allocated from Welsh Government in order for this draft Bill to work.

Governing Bodies

Whilst we do believe that the draft Bill could allow governing bodies the responsiveness to react to lower level needs, we are concerned about the duties placed upon governing bodies within this draft Bill. Governing bodies are made up of people with a range of expertise who volunteer their time. Indeed, most of our members (83%) were concerned that governing bodies would not have the expertise to identify and support children with ALN.

This draft Bill shifts the responsibility for children with additional learning needs from local authorities (LAs) onto schools. This could be helpful for lower levels of ALP, where a governing body, given the right resources, could act in a more timely and responsive fashion.

However, it is therefore important that governing bodies are properly equipped with the support, finances and expertise to identify and meet the needs of those with additional needs within schools. We do not believe that this is currently the picture in Wales.

Specialist Provision

During a statement and the evidence session with the Children, Young People and Education Committee on the 26th November, the Education Minister, Huw Lewis AM, indicated that the 'New Deal' for training will mean all teachers will be able to teach a fully "inclusive"[5] curriculum and that there will be less of a need for specialist learning provision.

Huw Lewis told the CYPE Committee:
"I think there's also a crying need, to my mind, taking things up the age range a little, for speech and language therapy to be, to an extent, part of the menu of skills that more and more teachers are able to develop and that's something, particularly through the new deal and the developments around initial teacher education and training, I've asked officials to take a look at how we can upskill teachers, so that there is more awareness and more capacity within schools in order to be able to meet some of these needs. But—. Well, the committee will take this as the committee wants to take it."[6]

Whilst we agree that there needs to be an 'upskilling' of the workforce in order to meet the needs of this Bill, we would be concerned about the expectation that teachers take on the roles of other professionals. Of course some teachers undertake speech and language tasks, particularly under the advice of Speech and Language Therapists.

However, teaching is already a profession in itself. We would not expect GPs to undertake complicated procedures. Similarly, we want to see a Wales where our teachers are supported by other trained specialists to ensure that children and young people receive the right support in order to fulfil their potential.

Section 29: Favouring mainstream schools

Whilst we can see the principle behind favouring mainstream schools, we have concerns with regard to how the draft Bill works in terms of favouring mainstream education.

Whilst it is welcomed that the parents would have a say about the mainstream education of a child, the child's own "views, wishes and feelings" – and the best place to meet their ALN - are missing from the draft Bill. The Bill should also consider the needs of the child or young person with additional learning needs.

Indeed, more than half (56%) of those members who responded to our survey felt that a mainstream setting will not generally help children with ALN – although many pointed out it depends on the individual child.

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[5] http://gov.wales/about/cabinet/cabinetstatements/2015/10279462/?lang=en
[6] http://www.senedd.assembly.wales/documents/s46943/26%20November.html?CT=2

There needs to be great clarity surrounding admission arrangements when a school has been named in a child's Individual Development Plan (IDP).

The New Deal

As mentioned within the ALNCo section (above) we remain concerned as to how the so-called 'New Deal' for the education profession will mean that all teachers are 'upskilled' to teach a fully 'inclusive' curriculum.

In the same way that the Code places unworkable responsibilities onto the ALNCo, we believe that the proposed changes for class teachers could mean a lack of support for children and young people with ALN. It is not acceptable to expect teachers to be able to meet the needs of all children with ALN through differentiation of teaching methods.

Only a quarter (25%) had specific qualifications linked to their ALN work at the moment – most at a post graduate level. However, who is going to fund and support the rest of the workforce sufficiently to take on extra responsibilities for ALN, let alone an ALNCo role? We would ask Welsh Government to make their plans clear.

Although three quarters (75%) of those who answered our survey said new qualifications would be helpful, with specific asks for CPD modules, dyslexia training and extra training in how to support children and young people with visual and hearing difficulties. Concerns about how the cost would be met were raised, as well as time constraints. One member commented: "we don't have the time for extra formal qualifications".

Whilst we broadly welcome increased support for the profession, we also believe there is a limit to the amount of support a teacher or lecturer can offer each individual. The "upskilling" of the workforce must not mean a reduction in individual support and funding for a child or young person with ALN.

Assessment

Whilst there is indication that the local authority or governing body will have made an assessment of a need for ALP for a child with ALN, it is unclear what the assessment will look like.

The Bill indicates the 'views, wishes and feelings' of a child will be taken into account, which is welcome.

However, the assessment process remains unclear. With no duty on health and an increased responsibility for governing bodies, greater clarity is needed.

Where a child or young person's ALN is "severe and complex" the local authority will have responsibility. However, who decides that the ALN is severe and complex and how they do that remains unclear and could cause issues in terms of funding arrangements, especially for governing bodies.

All (100%) of members who responded to the survey felt that there could be a problem if “severe and complex” needs are not properly defined. They noted that the lack of clarity could raise a series of issues and potential legal cases.

There was concern an assessment could be carried out by the ‘cheapest’ person, rather than the person who can best assess the needs of the child. One respondent to our survey noted: “It needs to be completely unbiased as if completed by an LA person.”

Greater clarity is needed to ensure the assessment is a clear, needs and outcomes focused process.

The IDP

The Code lacks clarity surrounding the nature of the IDP. Whilst we welcome the proposals to make the plan statutory for all those with ALN, the nature of the plan lacks clarity. Working on the assumption it is an annually reviewed document it will be resource heavy to create, but could also cause problems in terms of the time of year it is reviewed.

Ideally a child or young person with ALN will need to set their ALP during the first term of each school year – which would be a relatively fluid document which can change when all agree. However, this will be unworkable in large education institutions.

Four fifths of respondents said that gaining a ‘statement’ or legally enforceable document had become more difficult in recent years. And a similar number (81%) felt the IDP could help. However, respondents also raised serious concerns about timing and resources.

One member responding to the survey questioned whether the annual review is an improvement as they noted: “All our pupils on the SEN register have 2 individual education plans a year”.

More than nine out of ten (93%) would favour a template for the IDP in order to create greater consistency across Wales and also to create a document which is portable across LA and LHB boundaries. We were heartened to hear the Education Minister is considering a template for the IDP.

As he said to the Children, Young People and Education Committee:
“I do accept, actually, that there are issues, particularly around issues like portability, that make the idea of a template really quite an attractive one, in terms of making sure that we don’t have disconnects if children are moving around the system, as they do, of course.”[7]

The template must ensure that the IDP is carried out in a consistent fashion, is needs and outcomes focused, and has safeguards to make sure ALP is provided in a timely fashion.

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[7] http://www.senedd.assembly.wales/documents/s46943/26%20November.html?CT=2

Transition

Transition arrangements remain unclear. For those facing transition between educational institutions the Bill remains unclear. Will the current statutory review and transition plans remain in place? They appear only in terms of vague principles in the Code.

Will there be a clear expectation for the child or young person to attend a meeting with the next school or college before they attend, or will that institution attend a review meeting in the lead up to transition?

There needs to be clear guidance around transition including expectations of the current/next education institution. These need to be workable for the ALNCo and any staff involved, and timely for the child or young person, in order that any issues around transition are addressed and changing needs met.

Will there be a final IDP for those reaching the age of 25? More clarity about this is needed to ensure that young people get the right support as they reach 25.

Transport

Transport arrangements also remain unclear. The duty for local authorities to provide transport could be considered as part of the arrangements made under the IDP – with a duty placed on local authorities to meet the needs for travel for learners with an IDP. We would also seek clarity on whether this Bill will repeal the current law set in the Learner Transport (Wales) Measure?

Health and Collaborative working

We would welcome a duty specifically placed on health boards and health professionals to assist with the process of assessing a child or young person in terms of ALN and the ALP they will need.

In our survey, four-fifths of members who responded to our survey (84%) said that health was not involved enough in drawing up plans at the moment. Almost everyone (95%) said that a duty should be placed on health to make them take part in drawing up plans for children and young people.

Information sharing – if not coordinated by the local authority – should be undertaken with support from the regional consortia – who will be able to assist schools/ FEIs in terms of expertise.

We do recognise there are challenges with the current system. We do acknowledge there can be problems with the current system. For example, using multi-disciplinary teams, where LA and LHB boundaries don’t meet, can be a challenge.

There are examples of good working, where schools are working with local services such as CAMHS, speech and language therapy, occupational therapy and Paediatricians.

One response to our survey summed up:
“It is so important to keep channels of communication open between all interested/concerned parties. Delays in getting answers can prove a great frustration.”

We would also have expectations that collaboration includes information sharing between other agencies such as those involved in the youth justice system and pupil referral units (PRUs).

Further Education Institutions
There are a series of issues which are specific too, or more concerning in further education institutions (FEIs), where student populations are large and funding is under severe pressure. Young people also have specific issues as they transition from a more structured school setting and move towards independent learning arrangements.

FEIs are a corporate body and greater clarity is therefore needed on whether the Bill will mean greater collaboration between local authorities and FEIs. This should include clear transition arrangements as well as clarity on how the FEI will seek consent from individual students and how the local authority and school can share information with the FEI to ensure that any ALN are met.

There is a need for FEIs to be supported in being able to comply and a clear phased transition period to allow for capacity, additional duties and monitoring and creating and establishing procedures to be put in place.

We have described in detail some issues below which though not specific to FEI, are particularly relevant to them:

Qualifications and CPD
The ‘New Deal’ for the education workforce needs clarity around how it will work in an FEI setting. It is likely the ALNCo in an FEI is not a qualified teacher at present; therefore it is unclear whether they will be able to remain in their role without the qualification.

The reform to Initial Teacher Training must also include the FE sector.

CPD in terms of the New Deal is focused primarily on school teachers. Greater resource is needed to ensure that the New Deal – whatever that looks like – is extended to those working in FEIs.

Complaints and Tribunals
Under the Bill, young people are expected to make their own representations in order to challenge their IDP or ALP. We believe this places an unacceptable burden on young people with ALN. They should be able to choose who represents them.

The Tribunal system in general needs more clarity.

Specialist residential placements

Currently arrangements are in place which make decisions about whether a young person with ALN is able to attend a specialist residential placement more consistent across Wales.

Specialist provision or mainstream schooling decision should be based on what is best for the child or young person and represent their “views, wishes and feelings”.

As one respondent to our survey said:
“If [a mainstream setting is] adequately staffed some will benefit. Some will always need alternative provision and expertise.”

We believe that the current decision making process – decided by Welsh Government – is preferable to individual local authorities making this type of decision. We would also have concerns that the way the Bill is worded in terms of favouring mainstream placements, could prevent children and young people accessing such specialist support.

Work based learning
Greater clarity is needed on how students accessing work based learning support are to have their ALN met. Whilst apprenticeships are specifically excluded from the Bill, FEIs still need to meet the ALN of children and young people who are attending their college. This seems to need greater clarity about what ALP should be provided and how it will be funded.

Age range
We have concerns that instead of being education focused the Bill is only for those under 25. Many learners within FEIs are over 25 and some have specific funding arrangements. Will these continue? We would prefer that the Bill was education focused, rather than limited by age. Additional learning needs are not age specific so neither should the support be.

Members in the FEI sector were concerned about the implication within the Bill – or a possible misunderstanding of it by children, young people and parents – that all learners with ALN would be able to access further education up to the age of 25. FEIs cannot guarantee this.

Qualifications
The Code and Bill do not make any provisions about qualifications. Currently there are issues surrounding expectations of the Joint Qualifications Council, which require specific assessment for access requirements in exams. These are often an unnecessary duplication of existing assessments of young people with ALN. We would seek clarity on how the legislation could improve these arrangements and extend the information sharing to ensure great collaboration between organisations.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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To Whom It May Concern

I am writing having briefly scanned over the above mentioned document. I have been surprised by its non decisive and rhetoric nature.

This 35 page document could be summarized into a flow chart. The first issue is to quantify what "additional needs" constitute. There is mention of epilepsy, diabetes and being registered as disabled. As you know, a child can be registered disabled for Conduct Issues, which ideally should be addressed via a Statement of Educational Needs.

There is no guarantee that the school has to provide a plan for the child and all responsibility is passed onto the school to implement it. We know that schools are literally on their knees and now you expect them to implement a plan which they are not qualified to do. This is a health issue, therefore medical staff such as nurses should be responsible for helping devise the plan and review it. Ultimately I am referring to epilepsy and such alike.

As for displaying the plan in the staff room, I am left bereft. How degrading for a child's medical history to be displayed in such a manner, but I think that symbolizes the significance that is given to this plan, a piece of paper.

Children are being removed from schools by their parents, as the level of care offered, by over stretched staff, is falling below that which is acceptable. A child with epilepsy or diabetes should be totally allowed to participate in school life, but for the majority of schools they cant or wont take that extra step to support the pupils, they are barely coping themselves.

In a school of 1,000 it could be assumed that at least 10 students have significant medical health needs. The Government has a choice, go down the statementing route or put in place a robust health plan. This plan would have to be coordinated by a specialist nurse, and reviewed at least monthly, more in acute circumstances. The nurse should not be viewed as a threat to the teaches profession, but as a help relieving the pressure of drawing up, advising and reviewing the plan, freeing up teachers time. The money and time this will save the Government and teachers will be worth the investment. He or she could support more than one school.

The current proposal is flawed, at best, and lacks any substance or investment in vulnerable children's lives, who quite rightly have a right to a school education. It is currently insulting.

Kind regards

Rebecca Davies Jones

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Vikki Brown

Organisation (if applicable): Epilepsy Action Cymru
email / telephone number: vbrown@epilepsy.org.uk / 0113 210 8889
Your address: New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☒
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

Epilepsy Action welcomes the opportunity to comment on this consultation document. Epilepsy Action is the UK's leading epilepsy organisation and exists to improve the lives of everyone affected by the condition. As a member-led association, we are led by and represent people with epilepsy, their friends, families and healthcare professionals.

We feel it is important to set the context of our exploration of the consultation document by outlining the impact that epilepsy can have on a child's educational experience.

An estimated 32,000 people in Wales have epilepsy. Of these people, approximately 2,762 are of school age *(Source: Epilepsy prevalence, incidence and other statistics, Joint Epilepsy Council of the United Kingdom and Ireland, 2011 / Office of National Statistics, United Kingdom; estimated resident population by region; Mid-2010 Population Estimates)* For some children, epilepsy can have an effect on how easy or difficult it is for them to learn. There could be many possible reasons for this, including:

- The condition itself
- The cause of the epilepsy
- The effects of seizures
- Side-effects from epilepsy medicines
- Absences from school

A 2014 study of school children with active epilepsy in West Sussex showed that:

- Over half of the children found it more difficult to learn than other children
- Over half of the children had problems with their memory

- Just under half of the children had problems with the speed with which they processed information
- Just under half of the children were not achieving as much as they could at school. The greatest difficulties were in mathematics and understanding their work
- Sixty five per cent (65/100) parents reported that their child had difficulties with attention and concentration

(Source: The identification of educational problems in childhood epilepsy, Young Epilepsy / Esme Fairburn Foundation, 2014)

The effects of seizures

Epileptic seizures can disrupt normal brain activity, and this can affect memory. The confusion that can occur after seizures may also cause memory loss.

Some children have a lot of epileptic activity in their brain, but don't appear to be having any seizures. This can happen both when the child is sleeping and when awake. If this happens very frequently, it can also affect their memory and how they learn.

Depending on the type of seizures a child has, they may feel very tired or confused after a seizure. They may also have interrupted sleep which will make them tired. Feeling tired or confused can affect how well a child can learn.

Side-effects from epilepsy medicines

Some children may have side-effects that affect their learning. These could include drowsiness, dizziness, memory problems, problems concentrating and mood swings.

Absences from school

Some children miss parts of their education because they need time off school to go to appointments with the nurses and specialists who manage their conditions. They may also be absent as a result of seizures, recovery after a seizure or injuries from a seizure.

Epilepsy and behaviour

For some children, epilepsy can have an effect on their behaviour. There could be many possible reasons for this, including:

- The condition itself
- The cause of the epilepsy
- The effects of seizures
- Side-effects from epilepsy medicines

The consultation document

In general, we disagree with the proposed draft and find the content disappointing, as it fails to address both 'learners' and their 'healthcare needs' during the school day. The document appears to have been written very much from an education point of view and lacks clarity about the rights of a child who has healthcare needs that require input from staff during the school day.

Tone & Language

The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales. The draft does not place children at the heart of the document, which should be the motivation for this policy area.

Where parental/child engagement is championed in principle, it is often undermined in practice. On the one hand guidance suggests that “parents and learners should be active partners” (Section 2. P.12) and that it is unacceptable practice to “ignore the views of the learner or their parents/carers; or ignore healthcare evidence or opinion” (Section 4.p 26). Yet the guidance lays out clearly that in the case of Individual Health Care Plans “if consensus cannot be reached, the head teacher should take the final decision”. It is difficult to see how this is of help in the case of schools already failing to engage. Indeed we find no clear evidence from the document that learners with healthcare needs have been consulted as part of the process in formation of this document. Since they are a major stakeholder, more effort could have been made to engage patient and parent groups.

Outcomes

Whilst we welcome the Welsh Government’s intention to improve and update the current guidance document for managing chronic diseases in schools, we would expect new guidance and its accompanying framework to adopt measures that will reduce adverse variability in provision of care and that will standardise policies and procedures for schools as much as possible in a move away from the current voluntary framework.

In reading the draft Supporting Learners with Healthcare Needs, there is a distinct lack of progression since the 2010 guidance in increasing or improving support for children with medical needs at school. We therefore believe that the proposed draft guidance will produce the same variable and inequitable outcomes in access to education that currently prevail across Wales.

Many schools across Wales deliver good care and support. Indeed Epilepsy Action has awarded a number of our educational awards *the Edwards* to nominated schools in Wales over the last six years. The Welsh Government has the opportunity to fine-tune the care these schools provide, to learn from them and to share best practice so that all children receive equitable school care. The real challenge is how to improve support and care in schools who are disengaged and currently fail to deliver the appropriate care.

In order to improve the existing framework, we recommend the following be put in place as a matter of urgency:

1. **Nature of the duty: Statutory duty or Non-statutory duty?**

The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs needed to bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** (not should) make additional arrangements for supporting pupils at schools with medical conditions. Central to this is the provision that **all** children with medical needs receive an IHP. We are particularly concerned that draft guidance explicitly makes clear that 'not all learners with healthcare needs require an IHP' and that 'the head teacher should take the final decision'. Parents of children with medical needs are left with no recourse when a school's leadership refuses to implement an IHP, even if it has been advised by health care providers and the parents themselves.

Previous guidance in Wales has failed because of ambiguity across multiple demonstrable areas. Evidence shows that it's voluntary, non-directive approach means that it is ignored by a number of disengaged schools because it lacked clarity of roles and failed to set out basic requirements in delivering effective support. The new guidance will fail if this is not addressed. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties. Variability in provision of care provided in schools is a profound issue. As a UK-wide organisation, it is much more difficult to provide assistance and guidance to supporters in Wales, where there is no explicit duty on schools which covers medical needs.

Contact with families demonstrates that even when parents articulate their concerns to schools, some are unwilling to change practices to improve support systems. This leads to poor care for children and dangerous situations where procedures and safety systems are not followed. These children are at a disadvantage and are likely to achieve worse health outcomes at an increased cost to them and to the NHS. Parents will continue to be frustrated by Welsh Government guidance that is insufficiently specific and directive in assisting them in meetings with schools where they have genuine concerns that their child is not safe and is not being supported. The impact on families is significant, with both children and parents lacking confidence that the right care and expertise is in place.

If the new guidance framework does not state precisely what schools **must** do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by a number of schools. We fail to see how the proposed guidance makes any clearer what measures are required to be put in place in order to adequately support learners with healthcare needs and with whom the responsibility lies to ensure such measures are implemented.

2. The ability to deliver in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce.

There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. How do we reconcile voluntary roles with the provision of effective support for a child with complex medical needs when away from home? The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises, or take them completely out of school. Where this is not viable, sometimes they will put a child's health and education at risk.

Evidence from families and schools indicates that there are not enough trained adults to provide an adequate level of care for children with medical needs in a school setting, despite the high level of support provided by NHS staff. Many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care. The training of supply teachers also presents difficulties.

We therefore recommend that Welsh Government explores the implementation of any new guidance with the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs. In some circumstances, this could be achieved by a new directional role of the school nurse.

3. Practical omissions

We strongly urge Welsh Government to revise the draft guidance document to include practical advice with regard to food management and school transport that relates specifically to children with medical needs. In particular we are concerned that there is little to no reference to the importance of food management as an important facet of support for many children with medical needs, both in the context of emergency and non-emergency chronic conditions.

We would also like to emphasise the need for every child with medical needs to have in place and Individual Health Plan (IHP). The current draft is inadequate in this respect. There are a number of references to contingency plans, which largely could be solved with a solid IHP.

Timeline

Furthermore, we would like to raise our concern regarding the proposed June 2016 deadline for completion of the document. We feel that there has been a lack of consultation with stakeholders around this issue, including the engagement of children and families of children with medical needs.
We would be very happy to attend a meeting with Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance

document.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The use of bold font to imply information which has a legal duty is poor and does not focus the reader to the purpose of the document. It tends to suggest that anything not in bold is unimportant, which clearly is not the case. Ideally everything in the document would be a statutory duty.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These duties are not related to learners with healthcare needs".

The below examples are <u>some</u> of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.
- Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22.
- Throughout the draft, the inconsistent use of bold/non-bold text with regards to duties and/or suggestions is confusing. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing "must" duties as

well as “should” suggestions. This occurs throughout the document.

- Further optional clauses are evident throughout the document i.e. “IHPs can help” on page 22, “whether to prepare an IHP”. The draft also contains ‘If’ clauses, such as ‘If a policy is in place, it should be followed’ – does this mean this is optional?
- Interchangeable language and terminology is used throughout when referring to “statutory guidance” and “legal requirements”.
- Page 23 begins mid-sentence.
- Annex 2 ‘Useful Contacts’ section contains no contact information and is not in alphabetical order.
- There are dangerous errors in the document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.
- There is a lack of clarity around the term ‘staff’ consistently throughout document i.e. page 11 ‘staff should be clear when a risk assessment is required’ with no guidance on when this might be or which staff member would be responsible.
- The draft places duties on ‘other learners’ in emergency scenarios, which is an unusual approach to emergency procedures.
- The draft refers to ‘all necessary forms’ throughout but does not list any specific required documentation, such as a medical conditions policy.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

We welcome the more concise nature of the new draft guidance compared with the 2010 document but would raise concerns over the structure of the content/sections.

We would encourage a common-sense approach to the list of contents and would advise further consultation of those who might use the document. Many of the third sector patient support groups, who have a wealth of experience in producing parent/carer versions of guidance, would welcome the opportunity to be involved in this initiative.

The guidance document applicable to England, ‘Supporting pupils at school with medical conditions’ contains the following sections in a clear and concise manner:

- (i) The production, adherence and review of a school’s key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
- (ii) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
- (iii) Procedures for day trips, residential visits and sporting activities.
- (iv) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
- (v) Staff training and support.
- (vi) Unacceptable practice, liability and indemnity issues and complaints.

The current draft is not written in a format suitable for parents and carers and consideration should be given to produce a more easy-to-read version of the document.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	X ☐	**Neither agree nor disagree**	☐

Supporting comments

It is unclear which document Annex 3 is, as there is no such entitled document. In the absence of this, we will provide feedback on the document entitled 'Forms':

Form 1: 'Contacting Emergency Services'. The information on page 2 directly contradicts the guidance document. Page 2 advises staff to contact 999 in an emergency, whereas the guidance document signposts staff to NHS Direct. We would have considerable concerns if a school called NHS Direct instead of 999 in response to a child who had a history of status epilepticus and who was experiencing a seizure.

Form 2: 'Parental agreement for school/setting to administer medicine'. This form may not be suitable for every condition and is very similar to an Individual Health Plan. Having an IHP for every single child with a health care condition would be a far superior approach, allowing for the inclusion of information such as the prescribing physician's contact information – so that in an emergency where the parents are unable to be reached, the school has somewhere to go for advice specific to the child. It may also be appropriate to include more than one set of contact details for family members.

Form 3: Again, this is something that could be incorporated into an IHP.

Form 4: 'Record of medicine administered to an individual child'. A daily medicines log book is currently used which details the dosage given to a child. This form may seem long-winded for conditions that require regular medication and also duplicates existing paperwork.

Form 5: As above.

Form 6: 'Request for child to carry his/her own medicine'. Would this form be completed for older/secondary school children? It is not clear which age group the form should be used for.

Form 7: ‘Staff training record – administration of medicines’. Will this form replace the existing sign off sheets that healthcare professionals complete with schools? The form currently has space for only one trained staff member, which would not be adequate (usually two or more staff members receive training).

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

We would hope/expect to see the use of plain language and clear explanations given in any document explaining legal provisions. As such, we suggest that the opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. We would also raise concerns that the second paragraph contains several exceptions that could lead to gaps in multi-agency working.

Additionally, we would raise concerns that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is likely that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions. For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Ellis Peters
Organisation (if applicable): Chair of, & on behalf
All Wales Paediatric Occupational Therapy Netwo
email / telephone number: ellis.peters @wales.nhs
Your address: Children's Centre, Brecon Hospital,
Cerrigcochion Rd, Brecon, Powys, LD3 7NS

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	√
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	√ ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The guidance document is positive in that it encourages engagement of the child/young person and independence in their care where they are able, particularly in relation to self-medication.

Throughout the document 'inclusiveness' is a key theme and is positive in ensuring all settings actively enable the learner with healthcare needs to *fully* participate.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	√ ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The bold distinction of statutory guidance as opposed to general

advice is clear. We are concerned that settings however may naturally focus their attention on their statutory obligations and risk missing the general advice.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	√ ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Well structured and ease to find information.

P12 Sharing Information
A challenge here is that parents may withhold consent for Health to provide information to Education. Where there is a learner with Healthcare needs, sharing of this information is essential to ensure full participation and robust health, safety and risk management which becomes difficult if consent is withheld.
IT systems between Health and Education are restricted therefore information is mostly provided in paper format or by individual professionals through multi-disciplinary meetings. This can slow up processes and timeliness of healthcare plans.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	√ ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	√ ☐

Supporting comments

The supporting documents that are enclosed are useful in providing guidance. However the focus is almost exclusively on medication, as the draft document covers healthcare other supporting documentation templates would help to ensure greater consistency across Wales e.g moving & handling plan. However, although we agree that the Individual Healthcare plan should be flexible in its format and tailored to the individual; inclusion of an example utilising the headings on P23 would have been beneficial as it would encourage consistency across Wales.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	√ ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

- **The document has been issued it is stated to change the emphasis from "Access to Education and Support for Children and Young People with Medical Needs" guidance document to "Supporting Learners with Healthcare Needs". The content however still appears to focus primarily on the medical needs such as medication rather than include the wider healthcare needs of for example children with cerebral palsy, muscular dystrophy or cystic fibrosis who may require therapeutic input on a regular basis in school and the facilities these healthcare interventions require.**

- **The provision of specialist equipment in schools e.g. positioning, personal hygiene / self-care etc. in relation to healthcare needs has not been addressed. The responsibility for provision, funding and the timeliness of this can often be a contentious area to the detriment of the child's well being and we would look to this document to provide some clarity.**

- **There is little comment in this Consultation document regarding children/young people with complex needs who are receiving Continuing Care. For these children health have primary responsibility to ensure all risk assessments and individual healthcare plans are clear and robust. For these children (who are n in mainstream or special schools) the health authority need to ensure the education setting is aware of the IHCP and associated documents.**

- **Another area not addressed within the Consultation document is the need for timeliness of decision re school placement for children with complex healthcare needs. Issues can arise particularly in June/July for September admission. When decisions are made less than 4 weeks before the end of term getting professionals together to write IHCP is challenging and has delayed school start dates therefore disadvantaging the learner.**

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

<u>**33**</u>

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Bernette Venables (school nurse team leader) /Helen James (Head of Children's Public Health Nursing and Paediatric Services) /Ellis Peters (Head of Paediatric Occupational Therapy)

Organisation (if applicable): Powys Teaching Health Board

email / telephone number:
Bernette.venables@wales.nhs.uk/Helen.james99@wales.nhs.uk/ellis.peters@wales.nhs.uk
01547 521207

Your address: C/O Jane Moses, PA to Helen James, Ystradgynlais Hospital, Ystradgynlais, SA9 1AU

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
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	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	X
	Health professionals	☐

	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	X ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Yes, the guidance is very clear. It is also very positive in that it encourages engagement of the child/young person and independence in their care where they are able, particularly in relation to self-medication.

Throughout the document 'inclusiveness' is a key theme and is positive in ensuring all settings actively enable the learner with healthcare needs to *fully* participate.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	X ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Again, the format is very clear and presents the responsibilities of the local authority in an unambiguous manner
Furthermore the bold distinction of statutory guidance as opposed to general advice is clear. However there is concern that settings may naturally focus their attention on their statutory obligations and risk missing the general advice.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**X** ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Yes. The information flows in a sensible way. The flow chart for the development of the IHPs is very clear.

However with regard to Sharing Information (page 12) this may present a challenge as parents may withhold consent for Health to provide information to Education. Where there is a learner with Healthcare needs, sharing of this information is essential to ensure full participation and robust health, safety and risk management which becomes difficult if consent is withheld.
IT systems between Health and Education are restricted therefore information is mostly provided in paper format or by individual professionals through multi-disciplinary meetings. This can slow up processes and timeliness of healthcare plans.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	X ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	X ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Yes the forms included are very useful although it might be appropriate to include a sample health care plan template.

However other supporting documentation templates would be beneficial to ensure greater consistency across Wales e.g moving & handling plan. Furthermore although the Individual Healthcare plan should be flexible in their format and tailored to the individual, inclusion of an example utilising the headings on P23 would be beneficial as it would encourage consistency across Wales.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	x ☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Yes very helpful

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

It is thought that the additional list of useful websites is excellent.

The clarity around children who have significant healthcare needs and their absence from school is very helpful. Many parents feel pressured around attendance when their children have multiple health appointments.

How will WG assure themselves that this guidance is being implemented?

It would be helpful to see more advice about how training regarding certain health needs and emergencies should be provided for staff both in school and on transport.

More information needs to be given about ensuring that learners have appropriate environments to carry out their health needs, eg private toilet areas for catheterisation.

In the impact statement it is asserted that learners are given a voice, however in document's information sharing section not enough emphasis is given to consulting with the learner before sharing information with other learners.

It is felt that the provision of specialist equipment in schools e.g. positioning, personal hygiene / self-care etc. in relation to healthcare needs has not been fully addressed. The responsibility for provision, funding and the timeliness of this can often be a contentious area to the detriment of the child's well being and we would welcome this document providing some clarity on this issue.

There is little comment in this Consultation document regarding children/young people with complex needs who may need greater multi-agency input to ensure risk assessments and individual healthcare plans that are clear and robust.

Another area we feel this Consultation document could address is the need for timeliness of decisions regarding school placements for children with complex healthcare needs to ensure IHP are in place at the start of new terms and prevent a delay in the child starting school.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Dear all,

RE: Consultation response - Supporting Learners with Healthcare Needs

Having reviewed the draft guidance, *Supporting Learners with Healthcare Needs,* the Cystic Fibrosis Trust believes that, without further consultation that provides meaningful involvement, the guidance is not fit for purpose.

It is disappointing that, as a successor to the 2010 document, this draft guidance does not address the need for further and improved statutory guidance on how health conditions should be managed in schools.

This is a fundamental cornerstone of improving the learning experience of individuals with chronic healthcare needs, like cystic fibrosis, in Wales.

Furthermore, the effort to address the guidance to the needs of individual learners who have acute and chronic healthcare needs is misguided, in that the process, responsibilities and nature of designing sufficient support for these groups is distinct. The draft guidance serves neither group sufficiently.

It will fail to empower those involved in the education of pupils with medical needs to work together to form a clear set of guidelines, and does not provide adequate protection or promotion of both their rights and the rights of learners.

The Cystic Fibrosis Trust strongly recommends that a further stage of consultation is embarked upon, which involves stakeholders including learners, parents, healthcare professionals and education professionals, and draws on the skills, experience and knowledge of third sector organisations across Wales, in developing clear, user-friendly and fit-for-purpose guidance.

The Cystic Fibrosis Trust is ready and willing to engage and support all future development on supporting learners with healthcare needs.

Many thanks,

Nick Medhurst, **Policy Manager** & Becky Kilgariff, **Support Services Manager**

07813 455 409
Cystic Fibrosis Trust
One Aldgate, London, EC3N 1RE

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Tim Pratt

Organisation (if applicable): ASCL Cymru

email / telephone number: tim.pratt@ascl.org.uk

Your address:130 Regent Road, Leicester, LE17PG

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

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	Education professionals	☐
	Teaching Unions	x
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Clearly structured and easy to follow

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	x	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Helpful having the statutory guidance printed in bold.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Easy to find relevant information.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	**x**	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Very clear

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Zein Pereira

Organisation (if applicable):Afasic Cymru

email / telephone number: zein@afasiccymru.org.uk

Your address:
203 Titan House
Cardiff Bay Business Centre
Lewis Road
Cardiff CF24 5BS

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

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	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	X

	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	**X**	**Neither agree nor disagree**	☐

Supporting comments

Healthcare needs covers a broad spectrum of need including speech, language and communication needs. However the wording and examples in this document predominantly refers to needs that may require medication or may present a medical emergency.

The revised draft of Supporting Learners with Healthcare Needs does not address the links and overlaps with a child or young person's learning needs. This is important for learners with speech and language needs as their healthcare needs can also be considered educational needs because communication is so fundamental to learning and progression. There is case law on this point.

There is a lack of clarity about how the IHP will relate to the current IEP, Statement of SEN or Learning and Skills Plan. The IHP is not statutory and does not focus on learning and should sit alongside or inform but not replace statutory support for learning.

Any references made to learning needs that are linked to healthcare needs are too vague and do not offer any safeguards to protect the needs and rights of children and young people. This is evident in many sections: general principles, roles and responsibilities, creating an accessible learning environment, procedures and record keeping, training, review and throughout the chapter on Individual Healthcare Plans.

The guidance does not mention Person Centred Planning!

"It is also considered good practice to involve parents, learners and other professionals in the development of the school healthcare needs arrangements."

(page 6)

Afasic Cymru considers it essential that parents and learners are actively involved with their involvement considered central to meeting the healthcare needs of learners.

In this revised draft, teachers and support staff are directed to work with parents and specialist services if a learner is falling behind with their work. However a pro-active approach to identifying and assessing needs means that staff should not wait for children to fail before involving parents and specialist services. Disability awareness training and speech and language awareness training should be mandatory across educational settings.

The repeated recommendation in this document to 'develop' or 'make arrangements' is far too vague. The overarching principles guiding the governing body arrangements in this document do not currently:

- place the learner at the centre,
- define the importance of assessment by specialist /multi-agency services to identify the support required,
- mention outcomes.

We agree that the involvement of the School Nursing Services is important. However school nurses do not replace the need for specialist health advice into IHPs and may themselves need speech and language awareness training to support the identification of learners presenting with these needs.

We are concerned about the content of the information flow diagram that identifies whether an IHP should be put in place. The person who has overall responsibility for the development of IHPs needs to be appropriately qualified and this has not been clarified. The responsibility for identifying a healthcare need also rests with school staff and this is intrinsically linked to their knowledge and understanding of for example: speech and language needs. Gathering information needs to include assessment information from school staff and the multi-agency team with specialist services as appropriate. The identification of a need for an IHP needs to place the learner at the centre and include a range of settings –'head teacher' implies schools only. We are concerned that decisions based on a similar level of need may vary across settings and there does not seem to be a mechanism for parents to appeal a

refusal to set up an IHP, or if an IHP has not been finalised or implemented. Again the overlap with additional learning needs has been not addressed.

The statutory guidance on page 24 that states that the education setting assesses the risks to a learner's education, health and social well-being, does not include the important contribution of specialist services to accurate assessment.

The guidance to governing bodies and head teachers about what to include in an Individual Healthcare Plan again is too 'flexible' and centred on the administration of medication.

According to this draft, the IHP is intended to 'capture the steps which need to be taken to help a learner manage their condition and overcome any potential barriers to participating fully in education'. A more frequent review of the IHP is needed to ensure its effectiveness.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X**

Supporting comments

Highlighting statutory guidance, legal duties and general advice seems useful but much more detail is required where healthcare needs relate to learning needs and impacts on learning.

The document is far too 'flexible' and includes too many sections that introduce guidance with, 'may involve some or all of the following', when there are items such as 'teachers and support staff' and 'parents' on a list.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X**

Supporting comments

Information about how to relate the IHP to special educational needs is required. The
inclusion of Annex 2: Useful Contacts is important and although it needs to be expanded, we are pleased to be included.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X**

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	**X**	**Neither agree nor disagree**	☐

Supporting comments

The forms are too focussed on medication. A broader view of healthcare needs are
needed.

Question 6 – Outline of the legal framework Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X**

Supporting comments

Annex 1 does not refer to the legal duties on Health that may be relevant.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Professor Sally Holland

Organisation (if applicable): Children’s Commissioner for Wales

email / telephone number:

Your address:

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	X
	Individuals	☐

	Other	☐

Background information about the Children's Commissioner for Wales
The Children's Commissioner for Wales is an independent children's rights institution established in 2001. The Commissioner's principal aim, under the Care Standards Act 2000, is to safeguard and promote the rights and welfare of children. In exercising their functions, the Commissioner must have regard to the United Nations Convention on the Rights of the Child (UNCRC), as stipulated in regulation 22 of the Children's Commissioner for Wales Regulations 2001. The Commissioner's remit covers all areas of the devolved powers of the National Assembly for Wales insofar as they affect children's rights and welfare. The UNCRC is an international human rights treaty that applies to all children and young people up to the age of 18. It is the most widely ratified international human rights instrument and gives children and young people a wide range of civil, political, economic, social and cultural rights which State Parties to the Convention are expected to implement. In 2004, the Welsh Assembly Government adopted the UNCRC as the basis of all policy making for children and young people and in 2011, Welsh Government passed the Rights of Children and Young Persons (Wales)
Measure, which places a duty on Welsh Ministers, in exercising their functions, to have 'due regard' to the UNCRC.

My responses to specific consultation questions are below. I have not responded to every consultation question but only to those of direct relevance to my remit.

Introduction

Teaching staff and schools play a key and important role in the lives of children and young people.
Most children and young people are able to engage broadly in education, making the most of the individual talents, interests and abilities. However, occasions arise when children and young people are sometimes restricted from accessing education, notably, when there is a greater requirement to respond to the short and long-term healthcare needs. Once children and young people's more immediate healthcare needs have been met, it is vital that they are then supported to fully re-engage in an education that supports them to be the best they can be. However, I recognise that responding to children and young people's healthcare needs can sometimes be daunting for staff (for example, teachers) who have not received medical training. I, therefore, welcome the revision and consolidation of the guidance as presented within this document. I am also pleased to see that a Children's Rights Impact Assessment (CRIA) has been published alongside these proposals. However, it is my view that the consideration given to the United Nations Convention on the Rights of the Child (UNCRC) could have been strengthened within CRIA. This could have included greater analysis of the General Comments presented by the UN Committee on the Rights of the Child. You will note from the main text of my consultation response that greater consideration could have been given to:

- The role of education in promoting the holistic needs of the whole child – giving equal parity
of status to supporting the mental health and emotional wellbeing needs of children and young people;
- Working in partnership with children, young people and their families to secure the best
interests of individual children and young people;
- Strengthening guidance designed to improve access to schools and education for disabled
children and young people.

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

I welcome the consolidation of existing guidance contained within the *Access to Education and Support for Children with Medical Needs* document. However, I am concerned that the draft guidance has omitted pertinent information that will support teaching staff and schools to appropriately respond to children's medical needs, particularly in relation to supporting children and young people in specific circumstances; including pregnant learners and children with degenerative health conditions. The draft document should provide school staff with information and guidance that supports them to appropriately respond to meeting the healthcare needs of children and young people in specific/complex circumstances.

I welcome changing the title to *Supporting Learners with Healthcare Needs.* The title change implies a greater focus will be given to meeting the holistic healthcare needs of children and young people. This would sit in line with the UN Committee on the Rights of the Child's General Comments on Education and Health (General Comment 1[1] and General Comment 15[2] respectively). It implies that the draft guidance would give equal parity of status to supporting children and young people's mental health and wellbeing needs. It is, therefore, disappointing to note that the draft document provides little direction for schools to establish provision and policies that proactively respond to the mental health needs of learners.

As part of their involvement in my *Beth Nesa?|What Next?* consultation, children, young people and adults all reported concerns about the lack of support available to promote and protect the mental health and wellbeing of children and young people[3]. It is my view that teachers and other school staff are well positioned to make positive contributions to learners' holistic wellbeing. The draft guidance should seek to address this gap by ensuring that it gives due consideration to the needs of the whole child or young person. The promotion of physical health should not be seen in isolation to upholding children and young people's emotional and mental wellbeing. Introducing provisions for teachers and other school staff to recognise and respond to such needs would further Wales' implementation of the United Nations Convention on the Rights of the Child (UNCRC):

Article 6: (Survival and Development) Every child has the right to life. Governments must do all
they can to ensure that children survive and develop to their full potential.

Article 12: (Respect for the views of the child) Every child has the right to say what they think in all matters affecting them, and to have their views taken seriously.

Article 13: (Freedom of expression) Every child must be free to express their thoughts and
opinions and to access all kinds of information, as long as it is within the law.

Article 23: (Children with disabilities) A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the
community. Governments must do all they can to support disabled children and their families.

Article 24: (Health and health services) Every child has the right to the best possible health.

Governments must provide good quality health care, clean water, nutritious food, and a clean environment and education on health and well-being so that children can stay healthy. Richer countries must help poorer countries achieve this.

Article 29: (Goals of education) Education must develop every child's personality, talents and abilities to the full. It must encourage the child's respect for human rights, as well as respect for their parents, their own and other cultures, and the environment.

The guidance should include provision for teaching staff and schools to give specific consideration to exploring how they (in conjunction with other agencies) can meet the emotional and mental health needs of children and young people. From a rights-based perspective, this would include promoting children and young people's access to *"information and material…aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health"* (Article 17 of the UNCRC).

It should also consider how the learning experience can be maximised to support children and young people to develop the knowledge, skills and emotional resilience required to uphold their own rights, the rights of others and to appropriately resolve conflicts. It should give specific focus to combating:

"depression, eating disorders and self-destructive behaviours, sometimes leading to selfinflicted injuries and suicide…violence, ill-treatment, abuse and neglect, including sexual abuse, unrealistically high expectations, and/or bullying or hazing in and outside school."

To be considered inter alia, General Comment No. 4 (Adolescent health and development) expands on this further and draws attention to the provisions laid down by General Comment No. 14 of the UN Committee on Economic, Social and Cultural Rights:

"States parties should provide a safe and supportive environment for adolescents that ensures the opportunity to participate in decisions affecting their health, to build life skills, to acquire appropriate information, to receive counselling and to negotiate the health-behaviour choices they make. The realization of the right to health of adolescents is dependent on the development of youth-sensitive health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services."

In doing drawing attention to such provision, the guidance should give greater consideration to the State Party obligations laid down by the UN Committee on the Rights of the Child:

"(a) To create a safe and supportive environment for adolescents, including within their family, in schools, in all types of institutions in which they may live, within their workplace and/or in the society at large;

(b) To ensure that adolescents have access to the information that is essential for their health and development and that they have opportunities to participate in decisions affecting their health (notably through informed consent and the right of confidentiality), to acquire life skills, to obtain adequate and age-appropriate information, and to make appropriate health behaviour choices;

(c) To ensure that health facilities, goods and services, including counselling and health services for mental and sexual and reproductive health, of appropriate quality and sensitive to adolescents' concerns are available to all adolescents;"

Question 2 – The format/presentation of the revised guidance document Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The existing *Access to Education and Support for Children with Medical Needs* document provides a summary of key points at the beginning of each chapter. It would be beneficial to the reader for this to be retained within the new draft. It would support practitioners to clearly and quickly identify where the relevant information they require is located within the document.

Chapter 1 – Introduction

- **General principles in meeting the healthcare needs of learners**

I am pleased to see the introduction of general principles set out with the draft document. I
welcome the emphasis given to ensuring schools have effective healthcare policies and arrangements in place that take into account their broader duties around safeguarding and equal opportunity. However with no paragraph numbers or principle titles (for example ‘Partnership Working’), their presentation is unclear. It is also disappointing to note that the section makes no reference to the articles and key principles outlined by the UNCRC:

Article 2: (Non-Discrimination) The Convention applies to all children, whatever their race,
religion or abilities; whatever they think or say, whatever type of family they come from. It doesn’t matter where children live, what language they speak, what their parents do, whether they are boys or girls, what their culture is, whether they have a disability or whether they are rich or poor. No child should be treated unfairly on any basis.

Article 3: (Best Interests of the Child) The best interests of children must be the primary concern in making decisions that may affect them. All adults should do what is best for
children. When adults make decisions, they should think about how their decisions will affect children. This particularly applies to budget, policy and law makers.

Article 6: (Survival and Development) Children have the right to live. Governments should
ensure that children survive and develop healthily.

Article 12: (Respect for the views of the child) Every child has the right to say what they think in all matters affecting them, and to have their views taken seriously.

The textbox contained on page 5 should be moved under the 'General Principles' heading on page 3.

I would also like to see the text included within this box to specifically outline the principles of inclusivity and make a commitment to collaborative working.

Chapter 2 – Supporting learners with healthcare needs

The introductory text of this chapter states that *"It is also considered good practice to involve parents, learners and other professionals in the development of the school healthcare arrangements"* (p.6).

Whilst I agree with the sentiment of this statement, it is my view that such provision is integral to child-focussed practice. I would, therefore, like this provision to make explicit reference to Article 12 of the UNCRC and ensure that this is given statutory status. Please see suggested amend below:

"In line with Article 12 of the UNCRC, learners should be involved in the development of the healthcare arrangements for the schools. Governing bodies should also work collaboratively with parents and other professionals to develop school healthcare arrangements in order to meet the best interests of the child (Article 3 of the UNCRC)"

• Roles and responsibilities

I welcome the publication of the differing roles and responsibilities related to the varying stakeholders within the document. However, the presentation of information within this chapter feels disjointed and unclear.

The following text contained within the introductory paragraph of the section could be moved to the subsection entitled **b) Governing bodies** on p.7 of the draft:

***"Governing bodies should ensure the roles and responsibilities of all those involved in the arrangements to support the healthcare needs of learners are clear and understood by all those involved."* (p.6)**

The inclusion of *"The roles outlined below are in no way exclusive and their exact responsibilities may differ from one education setting to the next"* (p.6) underneath the above sentence seems contradictory to the intended purpose of the guidance. Whilst I recognise that roles may differ from one context to the next, it is my view that the draft guidance presented in this section should clearly identify and outline the minimum standards of expected practice.

a) Local authorities

As currently presented, I am not convinced that the presentation of subheadings and statutory duties outlined in **bold** text is appropriate. For example, the content provided under this section relates to statutory provision contained under other legislative mechanisms, i.e. Section 19 of the Education 1996 and Section 25 of the Children Act 2004, however, these duties are not highlighted in **bold** and their status is not obviously clear to reader.

b) Governing bodies

I welcome the guidance contained within this section. It is my view that the "must comply with applicable statutory duties, including those under the Equality Act 2010" should be presented in **bold**.

c) Head teachers

This section of the draft guidance should make reference to the varying duties upon head teachers and management committees of pupil referral units in Wales. As set out in guidance issued under the Education (Pupil Referral Units) (Management Committees, etc.) (Wales) Regulations 2014[7], such statutory duties include taking responsibility for an individual child's education, to have regard to the guidance in the Code of Practice on Special Educational Needs and to promote the wellbeing of pupils.

e) Parents and learners

Again, greater emphasis and reference should be given to Articles 3 and 12 of the UNCRC within the provision drafted under this subheading.

- **Creating Accessible Learning Environments**

In 2014, my Office published a spotlight report entitled *Full Lives: Equal Access?* [8]. This report highlighted inadequacies in the current system intended to increase access to schools for disabled pupils. My Office called for improvements to be made in this respect. It is disappointing to note that this section has not sought to strengthen the existing 2004 guidance[9] or improve the status of accessibility plans and strategies. I would welcome amendments to provide redress.

Chapter 3 – Individual Health Plans

I agree with the draft guidance presented in this section.

Chapter 4

I agree with the draft guidance presented in this section.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Please see comments mentioned in above answers

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

I agree with the guidance presented within this document.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Annex 1 is helpful in highlighting the main legal provisions associated the safeguarding the welfare of children with healthcare needs, however, this may be better presented in a table format. Page 28 refers to Section 17 of the Children Act 1989. The legal provisions outlined by this section have been repealed by the Social Services and Wellbeing (Wales) 2014.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the "Data protection" section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Andy McGuinness

Organisation (if applicable): Crohn's and Colitis UK

email / telephone number:
andy.mcguinness@crohnsandcolitis.org.uk
01727 734467

Your address: Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, Herts, AL1 3AW

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	X

	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	x	**Neither agree nor disagree**	☐

Supporting comments

In the UK, at least one person in 210 has Crohn's Disease or Ulcerative Colitis, the two most common forms of Inflammatory Bowel Disease (IBD). These distressing illnesses can start in childhood, and studies suggest that around a quarter of people with IBD were aged under 16 when they were diagnosed. There is evidence that shows that the prevalence of the paediatric population is increasing across the UK. A primary school teacher may only occasionally have a child with IBD in their school, but secondary school teachers are quite likely to have at least one pupil in their school with the condition.

Ulcerative Colitis is inflammation of the lining of the colon and rectum (the large bowel) which causes ulceration and bleeding. In Crohn's Disease, the walls and lining of the digestive tract become inflamed, swollen and ulcerated. Crohn's can occur anywhere between the mouth and the anus, but most commonly affects the small intestine (small bowel) or colon. It is not always possible to distinguish between Crohn's and UC – so some children may be given a diagnosis of Indeterminate Colitis or IBD Unclassified (IBDU). These are lifelong illnesses which may have periods of remission when there are few symptoms, but also periods of relapse when the disease is active and the symptoms are much harder to cope with. There is no cure at present.

In general, we find the content of the proposed draft disappointing, as it fails to address both 'learners' and their 'healthcare needs' during the school day. The document lacks clarity about the rights of a child during the school day who has healthcare needs that require input from school staff.

The need for a statutory duty

The tone and language used throughout the draft document is extremely passive, referring to actions that schools and local authorities "should" take rather than what they "must" or have a "duty" to do. We would like the language of the guidance to be strengthened because currently the rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England. This puts them at risk of an academic and health disadvantage in comparison.

We believe that a statutory duty should be introduced for schools in Wales in relation to children with medical needs. The Children and Families Act 2014 (CFA) came into force in England on 1 September 2014 and contains a statutory duty (Section 100) to support pupils with medical conditions. The Act CFA means that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. Central to this is the provision that all children with medical conditions receive an Individual Healthcare Plan (IHP).

Every child with a long term condition with an Individual Healthcare Plan
Crohn's and Colitis UK are concerned that the current guidance is weak on the implementation of IHPs for children with long term conditions. Whilst schools need a policy on supporting the healthcare needs of learners, given the diverse and complex nature of health conditions, it is also essential that those children with long term conditions have an IHP to caterer for their specific health needs. This should not be a decision left to the discretion of each and every individual school.

The current guidance sets out that not all learners with healthcare needs will require an IHP and that the Headteacher should take the final decision. However, it is our strongly held view that Headteachers are not the most appropriate professional to be making this decision, which should be based on individual health requirements. Furthermore, parents of children with medical needs are left with no recourse when a school's leadership refuses to implement an IHP, even if this has been advised by healthcare providers and the parents themselves.

For conditions like Inflammatory Bowel Disease, which are poorly understood and for which lack of awareness of the condition can lead to lack of support from non-healthcare professionals, we would be extremely concerned if Headteachers were the ultimate decision maker on whether a student receives an IHP to help manage their condition.

Therefore, Crohn's and Colitis UK would like to see all students with a long term medical condition receive an IHP, independent of the whims of the Headteacher.

Consistency of Medical Policies
The consultation document gives reason as to the underuse of the current guidance by education settings in Wales, as one of the key justifications for renewing the guidance. The fact that only 40% of education settings in Wales have used the current medical needs document to inform the creation of their own medical needs policies has created a disparity and inconsistency of care in schools across Wales.

We would therefore expect new guidance and its accompanying framework to adopt measures that will reduce this variability and standardise policies and procedures for schools as much as possible in a move away from the current voluntary framework.

Variability in the provision of care provided in schools is a profound issue for children and young people with medical conditions. If the new guidance framework does not state precisely what schools must do to deliver a safe learning environment, the new guidance framework will fail to address this issue.

Crohn's and Colitis UK are therefore very concerned that the proposed document does not make clear what measures need to be put in place in order to adequately support learners with healthcare needs and with whom the responsibility lies to ensure such measures are implemented. Given experience to date, it is only through statutory guidance that we will see consistency of approach to support learner policies.

Psychological effects of long term conditions
It can be very hard for children, particularly adolescents, to cope with the embarrassment of living with IBD. They dread having to rush to the toilet, having 'an accident', creating smells, and, as a result, being ridiculed or bullied.

Being on dietary treatment for IBD can also be difficult. The psychological effects of not being able to eat with your peers can be very significant, especially when the child or young person is surrounded by temptation and bombarded by food advertising. It can also be socially isolating if they cannot eat the same foods as their friends. Even for those not on an exclusive liquid diet for IBD, mealtimes can still be stressful and difficult if food is associated with symptoms such as cramping pain, vomiting and diarrhoea.

The guidance does not expressly deal with the psychological effects on a child having a long term condition. Whilst the document will not be able to identify the specific medical needs involved in all conditions, Crohn's and Colitis believe that support for a student's mental wellbeing should be explicitly covered within the guidance.

Food Management
A child or young person with IBD may have difficulty in eating a normal size meal – perhaps because they feel full after eating only a little food, or because they have been affected by pain or needing to go to the toilet during the meal. Their doctor or dietitian may advise eating

small amounts regularly from a wide range of foods in order to ensure that they eat enough food to meet their needs. Their diet may also be supplemented by proprietary liquid meals. All this may mean pupils with IBD will need extra or longer meal breaks. They may also need to avoid certain foods and to drink extra water.

Some pupils with IBD may be on dietary treatment as described earlier. If so, it may be helpful if the child could have access to a fridge in which to store the liquid diet. If a pupil has a nasogastric or PEG tube they may feel embarrassed or anxious about attending school with the tube in place and may need additional support and/or practical help.

We strongly urge Welsh Government to revise the draft guidance document to include practical advice with regard to food management that relates specifically to children with medical needs. In particular we are concerned that there is little to no reference to the importance of food management as an important facet of support for many children with medical needs.

The ability to deliver in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce.

There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs. Schools regularly articulate their concerns regarding their legal position in caring for children with long term conditions and view the lines of responsibility as unclear with the current voluntary system.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. How do we reconcile voluntary roles with the provision of effective support for a child with complex medical needs when away from home? The voluntary capacity means that some schools do not deliver support as they should, rely on parents to attend school premises and where this is not viable, put a child’s health and education at risk.

Evidence from families and schools indicates that there are not enough trained adults to provide an adequate level of care for children with medical needs in a school setting, despite the high level of support provided by NHS staff. Many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care. The training of supply teachers also presents difficulties.

We therefore recommend that Welsh Government explores the implementation of any new guidance with the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs. In some circumstances, this could be achieved by a new directional role of the school nurse.

Consultation and Timeline

Given the lack of prior engagement with stakeholders, including children and families with medical needs, Crohn’s and Colitis UK are concerned about the proposed June 2016 early deadline for completion of the document. We believe the involvement of health charities and those affected in the creation of the guidance could have been extremely beneficial.

Given the lack of consultation, short time frame for response and the lack of communication regarding this consultation, there is a risk that the Welsh Government will not receive as wide a response to this consultation as is merited by the need.

Crohn’s and Colitis UK would be more than happy to attend a meeting with the Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance document.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	**x**	**Neither agree nor disagree**	☐

Supporting comments

Crohn's and Colitis believe that the use of 'bold' font to imply information which has a legal duty is confusing and stylistically poor.
Bolding certain aspects of the document suggest that anything not in bold is unimportant and can be ignored. This is clearly is not the case as there are incredibly important parts not bolded, which seems to point so some level of inconsistency in this bolding policy. We would suggest removing the 'bold' font and replacing this with clear bullet pointed recommendation tables.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X**

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**X**

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	**x**

Supporting comments

Question 6 – Outline of the legal framework Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	**X**	**Neither agree nor disagree**	☐

Supporting comments

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Sense Cymru is the national organisation supporting and campaigning for children and adults who are deafblind and who have complex needs. We provide specialist information, advice and services to deafblind people, their families, carers and the professionals who work with them across Wales. We also support people who have a single-sensory impairment with additional needs.

1. Sense Cymru welcomes the opportunity to respond to the Welsh Government's consultation **'Supporting Learners with Healthcare Needs'**.

2. Academic estimates of the prevalence of deafblindness suggest that there are 1,024 children and young people in Wales who have Multi-Sensory Impairments (MSI) (1). An increasing number of children and young people who access support from Sense Cymru tend to have more than one need or a range of disabilities, especially those who have survived premature births or have complex medical conditions (2). For these reasons, many children and young people with MSI will require support from a range of health, social care and education professionals and may have several Plans from statutory bodies outlining this support.

3. You will be aware that the Welsh Government has put forward proposals to reform arrangements for children with Additional Learning Needs (ALN), including the proposal for a detailed, statutory Independent Development Plan (IDP) for all children and young people with ALN that outlines the Additional Learning Provision (ALP) they are entitled to receive to support their learning. There is little reference to this proposed statutory document and its relationship with the non-statutory Independent Healthcare Plan (IHP) within this current consultation.

4. Sense Cymru would like to see the relationship between the IHP and the IDP clarified to the effect that:

    a. Every child or young person who has a disability or medical need that affects the way they learn will require an IDP, even if they also have an IHP. Children and young people with a health need must not receive a non-statutory IHP instead of a statutory IDP.
    b. An IHP should be included as an appendix to the more detailed IDP for children and young people who have health needs as well as ALN.

5. We would be happy to provide further information on any of the points above should this be useful to the Welsh Government in taking this area of work forward.

Notes:

(1) Estimate based on Emerson report (2010) upper estimates and 2011 Census figures.

(2) ‘Making the case for play: findings of the Sense public inquiry into access to play opportunities for children with multiple needs’ Sense, 2016, p.4.

Dr Catrin Edwards
Policy and Campaigns
Sense Cymru
Catrin.edwards@sense.org.uk

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Supporting Learners with Healthcare Needs

Consultation Response Form	Your name: Adele Rose-Morgan Organisation (if applicable): Parent email / telephone number: adele.rose@ntlworld.com Your address: 102 Goetre Fawr Road, Killay, Swansea, SA2 7QU

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
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	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☒
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

Question 2 – The format/presentation of the revised guidance document Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 3 – The structure of the revised guidance document Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

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Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here: I am not really happy with **2. Supporting learners with healthcare needs :-**

It is also considered good practice to involve parents, learners and other professionals in the development of the school healthcare needs arrangements.

I feel that it should be a requirement rather than just 'good practice' as 'good practice' actually means nothing. Schools have restrained budgets and liaising with parents is way down their priorities at the moment. As a parent of a child with complex needs who is in a unit, his provision has been stripped and the leadership of the school and the governors do not understand the issues. Parents need more equality especially when there are complex needs, including health needs involved. In our experience, teachers often advise us with great authority about the health needs of my child, even though it is his parents who have been his key person and attended all the many consultant appointments. This is frustrating and time consuming. We need to be treated as equals in the system otherwise teachers will rarely see us as part of the solution but more as a nuisance. If inclusion is going to be effective then everybody HAS to work together as a team.

Just under that , in the same section under 'Roles and responsibilities', Local Authorities and paragraph 3 - ***must make arrangements to promote cooperation between various bodies or persons, which include the local health board and an NHS Trust providing services in the area, with a view to improving, amongst other***

things, the well-being of children in relation to their physical and mental health, their education, training and recreation8 .
Again this does not include parents!

Again in section b) Governing bodies, there is nothing about liaising with parents. I cannot tell you how this makes me feel. I need to advocate for my child. Teachers aren't medically trained. I am often even more expert about my child's needs than the medical professionals.

In section d) Teachers / Support Staff – what will happen if nobody volunteers?

f) NHS Wales School Nursing Services.- there is a need for this service to liaise with parents.

Creating an accessible learning environment – adequate toilet facilities need to be compulsory in every school. Excluding children due to their inability to use the toilet should NEVER be allowed!! Using the toilet is in the same category as eating and breathing – it is an essential need whatever the physical disability. My son needs help with going to the toilet and for much of his school life the toilet hasn't been sufficient close for him. A small change would have been welcome or even a willingness to talk to us about the issue. Another friend has a child who is very bright but has a range of health needs. His health needs are that he isn't yet physically aware of when he needs the toilet. The local education authority refused to adequately support him so despite being 7 years old he is still unable to go to school. This same child is restricted for attending school for a whole day because of feeding issues and his hypermobility but would benefit greatly from going to school part time. This flexible approach was not something the education authority would allow.

Social Interactions – My son is not able to attend breakfast club without me contributing £10 to pay for a person to assist him. He is unable to attend after school club as the timetable has created a 10 minutes differential (where he would be unsupervised) between the time my son finishes school in his unit, whereas the after school club is start time coincides with the finishing time of the rest of the school.

Sharing information - Teachers and support staff should have access to the relevant information – until recently our teachers didn't even have access to our son's up to date educational statement. I have been asking for a review of our sons risk assessment since last September (9 months ago). I was told by our local parent partnership keyworker just before Christmas that the head teacher had agreed to amend it but we are still waiting. I asked to have a meeting with the SENCO for 2 months and am still waiting. This shows how the school is not interested in accessing the latest information from parents.

Parents and learners should be active partners – We have been kept out of school life, communication is very restricted and parents are not encouraged to volunteer to help at the school or contribute to the development of learning plans or IEPs. Rapid changes have been taking place at the school without any communication. Staff turnover has been startling, with over 50% of teachers off sick and a high turnover of supply teachers. Our children are probably the most vulnerable and new TAs and teachers need to be reappraised of the child's needs, but this does not happen. We as parents need have equality in the process otherwise problems will occur.

Training - Crucially, this training may also involve input from the parents and the learners themselves. – This needs to be reworded to state 'Crucially, this training ***should*** also involve' and not '***may*** also involve input from the parents and the learners themselves'. I have had enough of teaching staff giving me 'expert' medical advice about my child when I go to all the medical appointments, they don't! When it says ***may*** it does not give us equality in the situation and frankly gets us nowhere. Also parents should be invited to all training and meetings regarding their child. Decisions about our son have been made without our input which has lead to poor decisions.

Complaints procedure - Many parents feel unable to engage with a complaints procedure. Writing letters to professional people is far too daunting. Often when your child has complex medical and healthcare needs dealing with schools and education authorities is exhausting. Dealing with the complex health and medical needs is enough without dealing with a battle. Parent advisory services are not truly independent from the local authorities and do not sufficiently challenge or question the LA.

Roles and responsibilities in the creation and management of IHPs – again parents need to be seen leading this. It is they who actually know what their child's needs are. Health professionals, together with the parents, should be advising the staff in the education setting. Parents really need more equality. In education, parents are seen as non essential or interfering. The balance needs addressing. You need to have more emphasis on parental involvement than you are. Teaching staff have a tendency to be authoritative even about things they know nothing about. Parents need to be seen as equal influencers/contributors in these situations to readdress the balance.

I would say that a couple of regular points of contact at the school would be useful. Due to rapid staff changes and turnover the whole school experience has been very distressing. Good communication can be easily improved for instance by direct telephone or email contact which will provide the essential regular communication.

4. Unacceptable practice – 'In general it is not acceptable practice to' – I would omit 'In general' as it is too woolly and open to interpretation.

To summarise –

- Parents and learners in partnership as equals is essential.
- Parents and learners to be seen as experts regarding their child's health needs in equal partnership with health care professionals.
- It should never be acceptable to exclude a child because of inability to toilet independently. It is an accessibility and equality issue.
- Head teachers, teaching and healthcare staff should not make any changes to any plans without agreement from parents.

- Transparency is essential.
- Toileting issues really need a good look at. It is a health need. It needs to be directly referred to in this document.
- Some wording needs to be less woolly. Schools and LA use the ambiguity to get out of responsibilities.

I am trying to convey the strength of my feeling. In the past 2 years my son who is in a specialist unit for hearing impairment has only had a quarter of his educational statement honoured. Other aspects of his provision which wasn’t so well-defined have been stripped away. It has been exceptionally distressing. My son has complex needs; he has one rare genetic condition and is currently being tested for another. Dealing with school has been the most horrendous parts of having a child with additional needs. I feel as if I have lost years of being there for my other children. I really want to change things for other parents. I believe that there is a way.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Catherine Hodder
Organisation (if applicable): Young Epilepsy
email / telephone number:
chodder@youngepilepsy.org.uk
Your address:
St Piers Lane, Lingfield, Surrey, RH7 6PW

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
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Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the

Access to Education and Support for Children and Young People with Medical Needs guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

Young Epilepsy welcomes the opportunity to strengthen support for learners with healthcare needs. We urge the Government to introduce a clear duty for schools to support learners with healthcare needs in primary legislation. This would ensure accountability across Wales and would set clear expectations for schools, learners and families.

In considering how best to support learners with healthcare needs, we urge the Government to work closely with children and young people affected by health conditions, their families, as well as the organisations that support them.

The draft guidance published for consultation is not clear and easy to understand. Our response recommends strengthening and clarifying sections of the guidance, as set out below.

Access to policies on supporting learners with healthcare needs
The guidance should require schools to publish their policies on supporting learners with healthcare needs on their website. Many young people with epilepsy feel stigmatised because of misconceptions about their condition. Young people will be more willing to be open about their healthcare needs if they and their families are aware of the support that the school has in place. Such openness is particularly important for fluctuating and less visible conditions such as epilepsy. Families should not need to request policies from schools – they should be readily available on their websites.

Impact of healthcare needs on learning
Throughout the guidance, greater emphasis needs to be placed on the potential impact of healthcare needs on learning. The overarching principles on page 5, for example, must include the following:

> *Staff understand the impact of learners' healthcare needs on their ability to learn.*

Research conducted by Young Epilepsy (2014) found that 95% of children with active epilepsy had a significant difficulty in at least one area of cognition or behaviour. Sixty per cent of the children participating in our study met the diagnostic criteria for at least one specific behavioural disorder despite only one third of these being professionally diagnosed.

The impact of epilepsy on cognition and behaviour is frequently overlooked. The guidance should make clear that staff need to receive suitable training on how their learners' healthcare needs affect their ability to learn. Staff should develop strategies to address any difficulties.

Young Epilepsy's research into inclusion in education (2013) showed that a significant barrier was a lack of awareness about the different ways in which epilepsy can affect an individual. Absence seizures, for example, can be mistaken for daydreaming and not paying attention in class.

Individual Healthcare Plans

The guidance should set a clear expectation that all learners with long term health conditions should have an Individual Healthcare Plan (IHP). Some young people with epilepsy may be seizure free for long periods, but it is important that schools are prepared if a seizure occurs and that they understand the wider impact that epilepsy may have on a young person's ability to learn.

The guidance should set out stronger requirements for what information should be included in an IHP:

- IHPs should include the impact of a learner's healthcare needs on their ability to learn as well as agreed strategies to address these issues.
- Where administration of medication may be required, a signature from the prescribing doctor or nurse specialist should be obtained.
- *'Details of the healthcare need'* (p. 23) should include descriptions of the symptoms of the condition.
- Emergency protocols should be included in addition to *'emergency contact details'* (p. 23).

The guidance should signpost schools and local authorities to organisations that support children and young people with specific medical conditions. Many of these organisations, including Young Epilepsy, have developed template IHPs tailored to the conditions concerned. For epilepsy this includes descriptions of the different seizure types experienced by the learner, the usual duration of such seizures and differing emergency protocols where needed.

Training

The guidance should state that schools should ensure that sufficient numbers of staff are suitably trained. The text on page 17 implies that one member of staff will be suitably trained:

> *If a trained member of staff who is usually responsible for administering medication is not available, the learner's Individual Healthcare Plan should set out how alternative arrangements to provide the support will take place.*

We are concerned that schools could interpret this to mean that parents may be called upon to provide support. This goes against the guidance set out on page 26, which states that it is unacceptable practice to expect parents to attend the education setting to administer medication or provide healthcare support.

Emergency procedures

On page 15 NHS Direct is mistakenly described as an emergency service. In an emergency, schools should call 999.

As mentioned above, it is crucial that emergency protocols are agreed as part of IHPs and that staff are suitably trained. This is particularly important for conditions such as epilepsy where seizures must be timed and emergency medication may need to be administered in the event of a prolonged seizure.

The Royal College of Paediatrics and Child Health (RCPCH) examined the cases of children with epilepsy who had received intensive or high dependency care in hospital following a prolonged seizure. RCPCH found that in nearly half the cases (47%), an appropriate trained first aider had not been available. The study also found that an ambulance had been called at an appropriate time in only 43% of cases (2013, p. 63). Out of the 36 cases examined in detail, eight children died during or following their admission to hospital (p. 58). RCPCH stated that *'there may be children in the community at risk of prolonged seizures for whom those responsible for the child's welfare may be unclear how or when to respond in the event of seizures'* (p. 62).

Complaints

The school's complaints procedure should be summarised in the policies for supporting learners with healthcare needs.

REFERENCES

- Royal College of Paediatrics and Child Health (2013) *Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies*. Child Health Reviews-UK, London: RCPCH
- Young Epilepsy (2014) *The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) Study*
- Young Epilepsy (2013) *What Helps? What Hinders?: Inclusion in Education for Children with Epilepsy*

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

It is crucial that schools, local authorities and families clearly understand the legal duties to support learners with healthcare needs. The format of the draft guidance risks creating confusion regarding what is mandatory and what is advisory. The use of bold throughout the document, for example, appears to emphasise statutory guidance, but not duties in law. The word “must” is also used outside the context of legal duties. This approach is unclear and does not help schools and local authorities understand what is expected of them.

The statutory provisions themselves are not explained clearly (on page 2, for example) and the reader is not given clear guidance on where to find authoritative legal information (see the introduction to Annex 1).

Further information is required on the provisions in the Equality Act 2010, such as the definition of a disability and how reasonable adjustments could be made. Under the Equality Act 2010, a disability is defined as ‘*a physical or mental impairment [that] has a substantial and long-term adverse effect on the [person’s] ability to carry out normal day-to-day activities’*. Without appropriate information, the reader might struggle to identify a less visible condition, such as epilepsy, as a disability. The document should clearly signpost relevant guidance issued by the Equality and Human Rights Commission.

The legal framework around learners’ management of their own medication is unclear. Presumptions both for (pp. 24/25) and against (pp. 14/15) self-management are presented in the guidance. Schools’ legal duties and best practice must be made clear in this respect.

Several sections of the guidance address confidentiality, privacy and information sharing. Schools’ legal obligations must be made clear throughout. Any information sharing arrangements, including photo charts, must be considered with sensitivity and should be done in consultation with the learner and their parents. Such arrangements should avoid the need for a learner to repeatedly explain their condition.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

The structure of the draft guidance is not easy to understand or navigate. Further consideration must be given to how readers will need to access the information. Such guidance should be suitable for parents in addition to schools and local authorities. Additional guidance should be produced for learners, to ensure that they understand what support they should expect.

It is unclear why arrangements around Individual Healthcare Plans (IHPs) have been separated from the rest of the guidance. All learners with long term health conditions are likely to benefit from an IHP. Such plans also clarify agreed procedures for the school concerned. It is unclear whether the forms in Annex 3 constitute part of an IHP.

The structure of Annex 2 (*'Useful contacts'*) is unclear and difficult to navigate. These organisations are a valuable source of information, training and support for schools, local authorities and families. For example, Young Epilepsy's template IHP is available online, alongside a simple questionnaire to identify how epilepsy might be affecting a young person's behaviour and learning: http://www.youngepilepsy.org.uk/for-professionals/education-professionals/resources-for-schools/useful-documents/. Our helpline can be reached on 01342 831342.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

It is unclear whether the forms presented in Annex 3 constitute part of an Individual Healthcare Plan (IHP). A template IHP should be included which can be adapted according to condition and individual needs.

Form 6 should be adapted to ensure that it can be used, where appropriate, to give consent for a learner to administer their own medication, not just carry medication. This is particularly relevant where medicine is stored in a designated place for learners to access. The form should also contain an agreed protocol with the learner for what to do if the learner refuses to follow an agreed plan.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☒	**Neither agree nor disagree**	☐

Supporting comments

Please see the response to Question 2.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

There is a typing error at the beginning of page 23.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Sylvia Penny
Organisation (if applicable): Welsh Association of ME & CFS Support
email / telephone number: Sylvia@wames.org.uk Tell: 029 20515061
Your address:

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
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Consultation questions

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Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	**Disagree**	X ☐	**Neither agree nor disagree**	☐

Supporting comments

Grateful thanks for being able to comment on this consultation document 'Supporting Learners with Healthcare Needs'. Also thank you for the additional time to complete our reply due to illness.

In general, we disagree with the proposed draft and find the content disappointing, as it fails to address both 'learners' and their 'healthcare needs' during the school day. The document appears to have been written very much from an education point of view and lacks clarity about the rights of a child during the school day who has healthcare needs.

Tone & Language

The tone and language used throughout the draft fails to adopt child-centred and health-based approaches to the provision of support for children with medical needs in Wales. The draft does not place children at the heart of the document, which should be the motivation for this policy area.

Where parental/child engagement is championed in principle, it is often undermined in practice. On the one hand guidance suggests that "parents and learners should be active partners"(Section 2. P.12) and that it is unacceptable practice to "ignore the views of the learner or their parents/carers; or ignore healthcare evidence or opinion"(Section 4.p 26). Yet the guidance lays out clearly that in the case of Individual Health Care Plans "if consensus cannot be reached, the head teacher should take the final decision". It is difficult to see how this is of help in the case of schools already failing to engage. Indeed we find no clear evidence from the document that learners with healthcare needs have been consulted as part of the process in formation of this document. Since they are a major stakeholder, more effort could have been made to engage patient and parent groups.

Outcomes

Whilst we welcome the Welsh Government's intention to improve and update the current guidance document for managing chronic diseases in schools, we would expect new guidance and its accompanying framework to adopt

measures that will reduce adverse variability in provision of care and that will standardise policies and procedures for schools as much as possible in a move away from the current voluntary framework.

In reading the draft Supporting Learners with Healthcare Needs, there is a distinct lack of progression since the 2010 guidance in increasing or improving support for children with medical needs at school. We therefore believe that the proposed draft guidance will produce the same variable and inequitable outcomes in access to education that currently prevail across Wales.

The Welsh Government has the opportunity to ensure that all children receive equitable school care. The real challenge is how to improve support and care for schools who are disengaged and currently fail to deliver the right care.

In order to improve the existing framework, we recommend the following be put in place as a matter of urgency:

1. Nature of the duty: Statutory duty or Non-statutory duty?
The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must (not should) make additional arrangements for supporting pupils at schools with medical conditions. Central to this is the provision that all children with medical needs receive an IHP. We are particularly concerned that draft guidance explicitly makes clear that 'not all learners with healthcare needs require an IHP' and that 'the head teacher should take the final decision'. Parents of children with medical needs are left with no recourse when a school's leadership refuses to implement an IHP, even if it has been advised by health care providers and the parents themselves.

Previous guidance in Wales has failed because of ambiguity across multiple demonstrable areas. Evidence shows that it's voluntary, non-directive approach means that it is ignored by disengaged schools because it was insufficiently directive, lacked clarity of roles and failed to set out basic requirements in delivering effective support. The new guidance will fail if this is not addressed. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties. Variability in provision of care provided in schools is a profound issue.

Contact with families demonstrates that even when parents articulate their concerns to schools most are unwilling to change practices to improve support systems. This leads to poor care for children and dangerous situations where procedures and safety systems are not followed. These children are at a disadvantage and are likely to achieve worse health outcomes at an increased cost to them and to the NHS. Parents will continue to be frustrated by Welsh Government guidance that is insufficiently specific and directive in assisting them in meetings with schools where they have genuine concerns that their

child is not safe and is not being supported. The impact on families is significant, with both children and parents lacking confidence that the right care and expertise is in place.

If the new guidance framework does not state precisely what schools must do to deliver a safe learning environment, the new guidance framework will fail to change the approach adopted by a number of schools. We fail to see how the proposed guidance makes any clearer what measures are required to be put in place in order to adequately support learners with healthcare needs and with whom the responsibility lies to ensure such measures are implemented.

2. The ability to deliver in practice

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce.

There are issues relating to low awareness, understanding and confidence of school staff in managing medical needs, in particular ME/ CFS.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. How do we reconcile voluntary roles with the provision of effective support for a child with complex medical needs when away from home? The voluntary capacity means that some schools do not deliver support as they souls and put a child's health and education at risk. They also open themselves up to legal challenge.

Evidence from families and schools indicates that there are not enough trained adults to provide an adequate level of care for children with medical needs in a school setting. Many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, are very reluctant for any staff to be responsible for medical needs. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care. The training of supply teachers also presents difficulties.

We therefore recommend that Welsh Government explores the implementation of any new guidance with the provision of training and the possibility of the creation of specific roles to provide an adequate level of support for children with medical needs. In some circumstances, this could be achieved by a new directional role of the school nurse.

3. Practical omissions

We strongly urge Welsh Government to revise the draft guidance document to include practical advice with regard to school transport that relates specifically to children with medical needs. In particular we are concerned that there is little to no reference to the importance of food management as an important facet of support for many children with medical needs, both in the context of emergency and non-emergency chronic conditions.

Exercise

The section on exercise needs to clearly state the need for parental and pupil input as exercise can be harmful to some pupils with chronic conditions. There is considerable dispute where exercise and ME/ CFS are concerned and this should be taken on board. If a pupil has medical evidence to say they should be excused from all physical education a quiet room for them to rest in should be available.

We would also like to emphasise the need for every child with medical needs to have in place and Individual Health Plan (IHP). The current draft is inadequate in this respect.

Period of absence

The Period of absence proposed i.e. 3 weeks is too long for any pupil to be without an education. Whether this be in one lump or over the school term. It takes too long at the moment for a local authority to put in home tuition and therefore the pupil is at significant risk of falling behind and also of not receiving a 'suitable education'. This can open up a legal challenge by parents on behalf of the pupil. Many schools do not provide pupils with work to do whilst at home ill even when requested by parents.

EOTAS

There is nowhere in this document that says about pupils who are too ill to attend school and the threat of being referred inappropriately to Social Services by schools and Local Authorities. It must be made clear that where there is evidence that a Child is to ill to attend school that any referral to Social Services for non-school attendance is inappropriate and should be discouraged in the strongest terms.

At present the current guidance does not work effectively for these pupils and it is imperative that providing a 'suitable education' for pupils who require education otherwise than at school is statutory rather than just guidance. This section should also suggest ways in which education otherwise than at school can be provided taking into account emerging and current technologies such as e-learning. It must also be remembered that some pupils will be too ill to be educated at all and this needs to be written into this document.

Learners who are older

For pupils who require to stay in education longer due to them missing substantial periods of education there should be a means for them to stay in education and receive a 'suitable education' until for example the age of 25 so that they get the same educational opportunities as their peers and to take into account their periods of absence from school prior to 16/18.

Integration

It is important that integration back into the school setting is always at the pupils speed and illness level and should never be forced. Sometimes there may be a need for reintegration to be graduated very slowly such as 1 hour a week to start and then being built up to a level and speed that there Pupils can cope with without making their condition worse. Sometimes it is not possible

to reintegrate pupils with chronic conditions back into the school setting and this should not be used as a Child Protection issue. Pupils and their parents are an important part of reintegration and when it is appropriate as they are the ones dealing closest with the pupils illness and know their own capabilities.

Timeline

Furthermore, we would like to raise our concern regarding the proposed June 2016 deadline for completion of the document. We feel that there has been a lack of consultation with stakeholders around this issue, including the engagement of children and families of children with medical needs. As a third sector organisation listed throughout the consultation and draft documentation, we were surprised that we were not notified of the launch of the consultation. The lack of communication regarding this consultation means that we now have a short time period for responses and there is an increased risk that Welsh Government will not receive as wide a response to this consultation as is merited.

We would be very happy to attend a meeting with Welsh Government and other stakeholders to inform any future work in this area and/or drafts of the guidance document.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We welcome the reference made to the child-centred United Nations Convention on the Rights of the Child but there is little reference to children's rights throughout the remainder of the document.

The use of 'bold' font to imply information which has a legal duty is poor and does not focus the reader to the purpose of the document. It tends to suggest that anything not in bold is unimportant, which clearly is not the case. We would suggest removing the 'bold' font and replacing this with clear bullet pointed recommendation tables.

The listed legislation does not explicitly mention medical conditions. The draft, which is a healthcare needs document, admits as much on page 5: "These

duties are not related to learners with healthcare needs".

The below examples are some of the inconsistencies found in the draft that relate to language, formatting and/or a lack of clarity:

- **Page 23 further supports the aforementioned ambivalence towards a child-centred approach, with the notion that IHPs should be flexible enough to "enable the education setting to choose", with no mention of what is appropriate for the needs and rights of children.**
- **Page 29 contributes further to the unclear nature of the draft, by encouraging the responsible body of a school to prepare and implement an accessibility plan (Equality Act 2010). This may not be appropriate for children with medical needs. Conversely, an Individual Healthcare Plan (IHP) will always be appropriate, but this is given an 'optional' status by the draft on page 22.**
- **Throughout the draft, the inconsistent use of bold/non-bold text with regards to duties and/or suggestions is confusing. For example, on pages 6 & 7 there is an interchangeable use of bold/non-bold text containing "must" duties as well as "should" suggestions. This occurs throughout the document.**
- **The existing suggestions of good practice have not changed since the 2010 guidance. As stated on page 3, these suggestions "may be required or desirable". If this is the case, we would query the need to highlight them in bold in 2016 and would raise concerns over current schools practice if Welsh Government feels that this needs to be highlighted 5 years after the guidance was originally implementation.**
- **Further optional clauses are evident throughout the document i.e. "IHPs can help" on page 22, "whether to prepare an IHP". The draft also contains 'If' clauses, such as 'If a policy is in place, it should be followed' – does this mean this is optional?**
- **Interchangeable language and terminology is used throughout when referring to "statutory guidance" and "legal requirements".**
- **Page 23 begins mid-sentence.**
- **Annex 2 'Useful Contacts' section contains no contact information and is not in alphabetical order.**
- **There are dangerous errors in the document i.e. advising those reading the guidance to contact NHS Direct in an emergency. NHS Direct is not an emergency service.**
- **There is a lack of clarity around the term 'staff' consistently throughout document i.e. page 11 'staff should be clear when a risk assessment is required' with no guidance on when this might be or which staff member would be responsible.**
- **The draft places duties on 'other learners' in emergency scenarios, which is an unusual approach to emergency procedures.**
- **The draft refers to 'all necessary forms' throughout but does not list any specific required documentation, such as a medical conditions policy.**

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We welcome the more concise nature of the new draft guidance compared with the 2010 document but would raise concerns over the structure of the content/sections.

We would encourage a common-sense approach to the list of contents and would advise further consultation of those who might use the document. Many of the third sector patient support groups, who have a wealth of experience in producing parent/carer versions of guidance, would welcome the opportunity to be involved in this initiative.

The guidance document applicable to England, 'Supporting pupils at school with medical conditions' contains the following sections in a clear and concise manner:

(i) The production, adherence and review of a school's key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
(ii) Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
(iii) Procedures for day trips, residential visits and sporting activities.
(iiii) Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
(v) Staff training and support.
(vi) Unacceptable practice, liability and indemnity issues and complaints.

The current draft is not written in a format suitable for parents and carers and consideration should be given to produce a more easy-to-read version of the document.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

N/A

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

It is unclear which document Annex 3 is, as there is no such entitled document. In the absence of this, we will provide feedback on the document entitled ‘Forms’:

Form 1: ‘Contacting Emergency Services’. The information on page 2 directly contradicts the guidance document. Page 2 advises staff to contact 999 in an emergency, whereas the guidance document signposts staff to NHS Direct.

Form 2: ‘Parental agreement for school/setting to administer medicine’. This form may not be suitable for every condition and is very similar to an Individual Health Plan and so would be a duplication of paperwork. It may also be appropriate to include more than one contact details for family members.

Form 3:

Form 4: ‘Record of medicine administered to an individual child’. A daily medicines log book is currently used which details the dosage given to a child. This form may seem long-winded for conditions that require regular medication and also duplicates existing paperwork.

Form 5: As above.

Form 6: ‘Request for child to carry his/her own medicine’. Would this form be completed for older/secondary school children? It is not clear which age group the form should be used for.

Form 7: ‘Staff training record – administration of medicines’. Will this form replace the existing sign off sheets that healthcare professionals complete with schools? The form currently has space for only one trained staff member, which would not be adequate (usually two or more staff members receive training).

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We would hope/expect to see the use of plain language and clear explanations given in any document explaining legal provisions. As such, we suggest that the opening paragraphs of page 27 do not go far enough in clarifying these to a lay person. We would also raise concerns that the second paragraph contains several exceptions that provide gaps for inaction in multi-agency working.

Additionally, we would raise concerns that the listed legislation and statutory duties relate to ALL children and are not specific to children with medical conditions. Consequently, it is likely that they will not be adequate/fit for purpose in resolving common practical issues that are regularly experienced by children and families of children with medical conditions. For example, the draft refers the reader on to the Learner Travel (Wales) Measure 2008 for more information on home-school transport. Medical conditions/needs are not explicitly mentioned in this Measure and it therefore fails to resolve common home-school transport issues.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

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Supporting Learners with Healthcare Needs

Consultation Response Form

Your name:
Organisation (if applicable): Royal College of Nursing Wales
email / telephone number: Anne.Muyang@rcn.org.uk
Your address: Royal College of Nursing Wales
Ty Maeth
King George V Drive East
Cardiff
CF14 4XZ

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☒
	Third sector organisations	☐

	Individuals	☐
	Other	☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The Royal College of Nursing Wales is overall supportive of the revised draft. The terminology used can be understood by professionals involved from each level.

It is concise, easy to read and follow with unambiguous guidance that addresses and meets children and young people’s rights under the following UNCRC Articles: 3, 4, 5, 6, 12, 13, 19, 23, 24, 28, 29, 31 & 32.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

This is well presented, highlighting statutory duties in bold throughout which results in a logical and structured document which is easy to read.

We believe that the use of the bold text identified throughout the paper highlights importance of the written text (Professionals roles and responsibilities and Unacceptable practice).

The paper clearly identities acceptable behaviours and unacceptable behaviours.
It provides the reader with the inside of the expectations put upon them.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We agree that that this paper is easily accessible with clear headings that lead you to the appropriate section in a timely manner.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers

Agree	☐	**Disagree**	☐	**Neither agree nor disagree**	☒

Supporting comments

The guidance overall provides adequate advice, but for absolute clarity it would be worth highlighting reinforcing that this guidance only applies when a pupil has a diagnosis of asthma but the personal inhaler (that the school would already be aware of) is for whatever reason not available.
Furthermore, we feel that this document could benefit from expanding on the changes to UK regulations allowing schools to hold emergency Medications

and the importance of this. It does not specifically identify salbutamol inhalers and the need for their use and the importance of this to the child with school. However it does identify the need for clear guidance, care plans and training to be in place to ensure safety.

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

We believe that the Annex 3 supporting documentation should be attached to the original document for easy accessibility.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☒	**Disagree**	☐	**Neither agree nor disagree**	☐

Supporting comments

The legal framework in Annex 1 provides a very clear and unambiguous presentation of the facts.

It is helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs. It clearly identifies the importance of safeguarding children in the educational setting, but could also be improved and geared towards the importance of the health professional (the role of the school nurse).

This would be in regards to liaising with school staff to improve safeguarding within the school setting through multiagency working and highlighting concerns regarding children’s safety. This would ensure that safeguarding concerns aren’t missed.

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

The Individual Healthcare Plan flowchart is particularly useful providing a clear explanation and identification of roles and responsibilities that will ensure schools are in a position to plan in advance to meet pupil’s needs.

The realistic explanation of what is expected of an NHS School Nurse is welcomed professionally as to date this has been an issue in some Local Authority areas.

The RCN is the world’s largest professional union of nurses, representing over 430,000 nurses, midwives, health visitors and nursing students, including over 25,000 members in Wales. The majority of RCN members work in the NHS with around a quarter working in the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing.

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

Responses to consultations are likely to be made public (please see the “Data protection” section in the Consultation Document), on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

Supporting Learners with Healthcare Needs

Consultation Response Form

Your name: Jessica Turner
Organisation (if applicable): UNISON Cymru Wales
email / telephone number: j.turner@unison.co.uk
02920 729413
Your address: UNISON House, Custom House Street,
Cardiff CF101AP

Responses should be returned by **29 April 2016** to:

Additional Learning Needs Policy Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: additionallearningneedsbranch@wales.gsi.gov.uk

Category of respondent	Schools	☐
	Special schools	☐
	Special Educational Needs Co-ordinators	☐
	Further education sector	☐
	Preschool organisations	☐
	Education professionals	☐
	Teaching Unions	☐
	Local government	☐
	Work Based Learning organisations	☐
	Local Health Boards	☐
	Health professionals	☐
	Other public sector organisations	☐
	Third sector organisations	☐
	Individuals	☐
	Other – Education union UNISON,	√

		☐

Consultation questions

These questions should be read in conjunction with the draft *Supporting Learners with Healthcare Needs* guidance document, which replaces the *Access to Education and Support for Children and Young People with Medical Needs* guidance document. Question 4 should be read in conjunction with the *Guidance on the use of emergency salbutamol inhalers in schools in Wales (2014)* document.

Question 1 – The content of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear and easy to understand?

Agree	☐	Disagree	☐	Neither agree nor disagree	☐

Supporting comments

The brevity of the revised document in comparison to the current guidance is welcomed. Whilst it is more concise than the previous guidance, the layout could be more accessible.

Question 2 – The format/presentation of the revised guidance document

Do you agree that the revised draft *Supporting Learners with Healthcare Needs* guidance document is clear in its presentation of the legal duties and advice for governing bodies and local authorities? This includes the presentation of the content which would be issued as statutory guidance (in bold font); information which is a summary of legal duties; and general advice.

Agree	☐	Disagree	☐	**Neither agree nor disagree**	☐

Supporting comments

The guidance should be firmer on the fact that no member of support staff can be compelled to administer medication. Whilst the references to all staff are an improvement on the previous guidance which focused mainly on teachers, the reality is that teachers are far less likely to come under pressure to do these tasks. The whole school team need to

recognise that it is not automatically the job of the support staff member to do administer medication and support health care needs.

The term volunteer is not necessarily helpful in this context, nor is the reference to contracts and terms and conditions as we know these can be easily varied with little reference to the consent of the individual. Furthermore, we've seen Single Status job evaluation exercises undermine the specific roles undertaken by "volunteers" by the removal of allowances and specific job titles relating to the administration of medicines and personal care.

In many Local Authorities, "administration of medicines" is now a standard duty in most Teaching Assistant job descriptions, even at Level 1. We know of cases where refusal has resulted in the threat of dismissal through disciplinary action or consideration the refusal to do these tasks looked at unfavourably during redundancy selection.

Our members also report being compelled to make potentially risky decisions about the administration of medicines that in any other context would be the responsibility of a suitably qualified health care practitioner.

Question 3 – The structure of the revised guidance document

Do you agree that the revised *Supporting Learners with Healthcare Needs* guidance document is structured clearly? Are you able to easily find the information you need or want to know by using the revised guidance document?

Agree	☐	Disagree	☐	**Neither agree nor disagree**	☐

Supporting comments

The sections need to be split down further. Sometimes too many bullet points follow on from sub headings (a,b,c,d etc) going over pages making it difficult to relate the information back to the original heading.

See additional points at the foot of the document.

Question 4 – The Guidance on the use of emergency salbutamol inhalers in schools in Wales document (2014)

Do you agree that the *Guidance on the use of emergency salbutamol inhalers in schools in Wales* document provides adequate advice to schools and/or local authorities on the changes to UK regulations allowing schools to hold emergency salbutamol inhalers?

Agree	☐	Disagree	☐	**Neither agree nor disagree**	☐

Supporting comments

Question 5 – Additional forms for the Supporting Learners with Healthcare Needs

Do you agree that the separate, supporting documentation (Annex 3) provided with the Supporting Learners with Healthcare Needs document is sufficient for your needs? If you disagree, please use the box below to suggest any potential additions or changes to these materials.

Agree	☐	Disagree	☐	**Neither agree nor disagree**	☐

Supporting comments

Every child with a medical condition should have an individual healthcare plan. The level of detail will depend upon the complexity of the medical condition(s) but for clarity it is important that every learner has one.

Question 6 – Outline of the legal framework

Is the legal framework annex (Annex 1) helpful in highlighting the main legal provisions associated with safeguarding the welfare of children with healthcare needs?

Agree	☐	Disagree	☐	Neither agree nor disagree	☐

Supporting comments

Question 7: If you have any related issues or comments in addition to the points above, please use this space to report them:

Please enter here:

Some specific points not already covered in our response are detailed below:

Page 7 b) Governing Bodies:

Under the heading b) Governing Bodies on page 7, the opening paragraph should be in bold as it refers to legislation and begins “must comply...”

Under the same heading b) Governing bodies, the second paragraph should be amended from “should” to read “*Must* make arrangements...” and “*must* include having a policy on healthcare needs...” This is essential if there is to be any overall accountability for adequately supporting learners with health care needs.

Page 8 under heading d) Teachers / Support Staff:

The sentence “this role is entirely voluntary” should be changed to “No member of staff can be compelled or required to administer or supervise medication.” The current wording (alongside all of the other caveats) assumes that someone will volunteer, and therefore, does not deal with a likely scenario where nobody volunteers and the learner is left exposed to risk, harm or is unable to participate in mainstream activity. Without the protections afforded to teachers through their terms and conditions, usually this person will be a member of support staff more vulnerable to accept instruction from the Head teacher or school leader. The Welsh Government should acknowledge this likelihood and build in protections through stronger guidance on the roles of those staff.

In addition, the following sentence should be added:

"There should be no expectation that a non-healthcare member of staff will make independent decisions about a learners care; instead they should refer these to a parent or registered healthcare professional."

Also see above points about altered contracts / terms & conditions which could be seen to contradict the strength of the term "voluntary" or our preferred wording of "cannot be compelled or required." **UNISON is requesting early discussions about this point prior to the publication of the revised guidance**.

At the end of paragraph d) before the bullet points the word *"all"* should be added so that the sentence reads "the education setting should ensure *all* staff:" This makes clear that the responsibility for understanding healthcare needs of learners rests with the whole school team and not just one or two individuals.

Page 10 under the heading NHS Wales School Nursing Services:

There needs to be a greater role for the school nursing service in the administration of medicines in schools. School nurses and other health care professionals should also be aware that no member of staff can be compelled to administer medication or perform the duties otherwise delivered by the healthcare professional. Increased resource allocation for school nursing must be addressed.

Page 16 under the heading Training:

The first line in bold should be changed from "Governing bodies should..." to Governing bodies ***mus*****t**..." Similarly it is crucial that the following wording in the second bold sentence is changed to "Governing bodies ***must*** also ensure staff who..." The exact wording on this point will need to be altered if UNISON's earlier submission about the use of the term volunteer is accepted.

Prescribed medicines should not be administered without training. This point needs to be clear.

Specific (accredited) training should be provided on a named child basis to avoid the situation where a member of staff is deemed to be competent to support any child with medical needs just because of past training or experience. Identifying appropriate training should follow discussion (initiated by the head teacher) with school staff, specialist health care professionals, parents and the NHS Wales school nursing service. The training should be carried out by a health care professional.

A sufficient number of trained staff should be available for off-site activities. It can be a time of increased stress and anxiety for staff, therefore, the need for staff breaks must be taken into account. This may result in an increase to the normal staffing compliment, particularly if staff are required to be awake at night to deal with health care needs.

For UNISON members, the following issues are key:

- All learners with medical needs must have an individual healthcare plan;
- The governing body must regularly audit their policies and ensure individual healthcare plans are being followed;
- Attention must be given to the school nurse workforce in order for the guidance to be effectively implemented;
- Funding for appropriate staffing and relevant training is crucial to implementing the guidance effectively;
- Safeguarding provisions (for the sake of staff and learners) need to be considered more fully, for example staff working in pairs
- The whole team needs to be aware that school staff are not required to support pupils with medical needs so that staff are not put under undue pressure and pupils at risk;
- School staff providing healthcare support should receive specific and accredited training on a named-child basis, with access to ongoing updates and appropriate supervision. Refresher training should be provided at least once a year;
- There should be no expectation that school support staff will make an independent decision about a learners care - instead they should refer to a parent or registered healthcare professional;
- The governing body should also consider and include in the plans which tasks should **only** be carried out by a registered healthcare professional;
- The remuneration of school support staff providing healthcare support to learners should be reviewed by schools so that it takes account of the additional responsibilities, knowledge and skills required to support children with health needs.

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Dear Sir/Madam.

Please could you take the following points into consideration.

SEEKING RECOGNITION, DIAGNOSIS AND SUPPORT OF AUDITORY PROCESSING DISORDER (APD) IN THE UNITED KINGDOM

To whom it may concern - we ask for legislation and government funding to be put in place for:

Auditory Processing Disorder (APD) to be fully, routinely and mandatorily recognised as a disability in the United Kingdom by all schools/colleges/universities, medical and educational professionals, NHS Trusts, LEAs, employers, benefits agencies and support agencies;

Standardised testing and diagnosis, to the level of that provided at the APD Testing Centre at Great Ormond Street Hospital, London/GOSH (for children) and University College London Hospitals/UCLH (for adults), to be routinely and mandatorily provided at NHS APD testing centres, available to all, UK-wide;

Training of more specialist audiologists to provide such testing, with testing standards to be professionally monitored for accuracy, and impartiality from funding by therapy providers;

Full support and all appropriate individually tailored accommodations to be routinely and mandatorily provided at schools and in further education, recognition for the need for APD support via EHC Plans, providing every child and adult with APD in the UK access to what they currently do not have, namely:

"efficient full-time education suitable —
to his age, ability and aptitude, and
to any special educational needs he may have" according to the Education Act 1998.

Full support and all appropriate accommodations to be routinely and mandatorily provided for adults with APD at all Job Centres, benefits and support agencies and by employers - according to the Equalities act 2010 and article 14 of the European Convention.

Failure to do so, which sadly is the status quo, is disability discrimination. People with APD in the UK have a right to the same level of support as any other disability.

APD FACTS

- Auditory Processing Disorder, known as APD, is an (as yet) incurable, lifel disability which, according to the most recent professionally accepted definit 'affects the way that the brain processes sound including speech'. In real term means that people with APD have difficulty understanding and retaining spo information.
- APD has an often profound impact on all aspects of a person's life in the area communication, socialisation, education, career choices etc. People of all ages APD need lifelong support at home, and accommodations school/college/university and in the workplace.
- APD can occur in people with perfect hearing or hearing loss but it does not af hearing, which is why the hearing impaired organisations will not support it.
- APD affects everyone uniquely and with varying severity, and each sufferer need individually tailored support.
- APD can affect people randomly and intermittently, with effects that fluctuate wi even during one day or one hour – which is why it is difficult for people to accept a sufferer can understand speech at one time and not another, and which ma APD one of the 'invisible disabilities.'
- APD has been estimated to affect up to 3% to 5% of UK children based population of 60 million (birthdate 13 per 1000, according to the latest research, wit taking into account undiagnosed adults) and it has been identified as being on the main causes of dyslexia (known as auditory dyslexia) with research ongoin that area.

- APD can be identified from an early age and it is diagnosed from the age of 7. leading centre of excellence in the UK is the APD Testing Centre at Great Orm Street Hospital, London and the only professionals qualified to diagnose it specialist audiologists.
- With a prevalence rate of about 5%, about 31,250 testing slots are needed a for the whole country (which means we need at least 125 centres seeing about patients a year). Currently GOSH can only test about a handful of NHS APD patie a week and their waiting list is 18 weeks long - mostly from parents researchi themselves and seeking referral, because so few professionals even know ab APD. With increased awareness of APD, we see that the waiting list and the nee more testing centres will increase exponentially.
- In addition to those diagnosed with APD, about 30% of those tested who don't the criteria for a full APD diagnosis are diagnosed with auditory processing issue difficulties, which still need the same support.
- APD is thought to be neurological in origin, caused by damage to the brain. often inherited, with a genetic cause, and is therefore present and often notice from birth – if a child appears hard of hearing yet hearing tests show no hearing l that is a primary indicator. In some children, it can affect the acquisition of spee another indicator (if a child cannot adequately process speech sounds, they will be able to effectively reproduce them- which can lead to dyslexia issues in s children).
- There are many other difficulties and many possible acquired causes, such frequent ear infections leading to glue ear; head injury; brain damage from epile or other injury; maternal drug or alcohol abuse or other damage in utero or at b also there have been links to other conditions such as ME and Down's Syndro and many other possible causes are still being identified. The cause makes difference to its effects, or how it is supported.
- APD rarely exists in isolation. People with APD usually have other co-existing unrelated invisible disabilities to deal with too (seen in about 90% of those alre presenting for testing) which can make coping with APD even harder, because conditions impact on each other and compound the difficulties of APD and vice ve e.g. Visual Processing Disorder, Tinnitus and/or Hyperacusis.
- APD even has some apparent characteristics in common with other invis disabilities (ADD/ADHD/Autism/Sensory Processing Disorder), which makes it ha to isolate and identify and APD can be misdiagnosed or it is missed entirely by be masked by other possible conditions.
- APD does not affect intelligence. In fact those with APD often have ama compensatory gifts.
- People with APD can lead happy, successful lives, using their gifts and strengt but only if they have recognition, validation, acceptance, accommodations and right sort of support, which most of them currently lack.

Notably:

a. There has been diagnosis for APD available in the UK since 2004 (at GOSH, links section below).

b. APD is acknowledged by the World Health Organisation and has a classificatio the International Classification of Diseases (ICD) (which lists conditions too) - u the section ICD 9, as ICD-9 388.45 and ICD-9 388.40 and the Medical Sub Headings as MeSH D001308.

c. The NHS has a web page about APD (see links section below) - yet is still not recognised and supported by all medical professionals in the UK; most audiolog

GPs and paediatricians are unaware of its existence.

d. The British Society of Audiology has a special interest group to study it (see li section below)

e. The Medical Research Council Institute for Hearing Research funded the resea that led to the testing being introduced on the UK.

Yet APD is still not widely known or recognised in the UK; support is sparse and pare children and adults with APD have to fight against the medical, education and bene systems daily, for what should be automatic.

Further information

Some other hospitals around the UK test for APD, but do not provide the level of tes available at GOSH – and there are even private assessors 'testing' for APD who don't e use approved tests, who 'diagnose' auditory processing difficulties (which is not a diagno of APD) and selling programs and therapies (none of which have been scientifically pro to have any great or lasting benefit. Everyone with APD is affected uniquely - espec considering their individual level of severity, co-morbid conditions and coping strategies which is why a one-size-fits-all approach will not work. Children have even been testec private assessors and told that they didn't have APD, only to be diagnosed on assessm at GOSH with severe APD. That is why <u>standardised</u> testing and diagnosis to the le which is provided at GOSH is urgently needed UK-wide, as well as professional monito to stop misdiagnosis, ineffective testing and unscrupulous people taking advantage vulnerable families.

Accurate early diagnosis of APD is essential, but diagnosis is just the start. Early diagnosis means that support is implemented sooner and development of coping strategies can be encouraged earlier, so the child has a better chance of educational achievement (particularly as the auditory processing system of the brain is not fully developed until age 12/13). APD does not affect intellect and APD is not a learning difficulty - it causes them, among other things. An EHC Plan is vital for each child with APD to secure the help they need throughout their education - because without it, schools fail to provide it. Immeasurable damage is currently being done by professionals in the field of education, who fail to acknowledge APD, and as a result, adequate support is being denied to most children with APD. This is due to ignorance about this condition and/or reluctance/failure by educational professionals (teachers, SENCOs and Educational Psychologists and LEAs) to acknowledge and support APD, even when valid diagnosis is obtained and specialist reports are provided.

Supporting any child suspected of having APD pre-diagnosis can have a huge benefit to by putting in place ongoing individually tailored strategies, just as if the child had a diagno of APD, especially as a child can be suspected of having APD at a very early age cannot be tested till age 7. The effects of APD become worse as children move secondary school and beyond, when work demands are greater and stress makes effects of APD worse (as does illness and tiredness), so more support is needed. Cost is usually a factor in supporting a child with APD – in fact, most accommodations for APD c nothing; they are just good teaching.

APD cannot be cured, so sufferers need to learn to live with it and get around it, by using coping strategies, utilising their own unique gifts and skills, learning style and strengths. Self-advocacy skills are vital for someone with APD - the ability to know how it affects them as an individual and being able to ask for the unique accommodations that they need and are legally entitled to receive. Also essential is acceptance by family and friends, which can be absent when it is so infrequently recognised and validation is denied. If unsupported at school APD can cause the sufferer extreme stress and people with APD often develop anxiety or depression - even children - which cannot be allowed to continue. APD can be devastating to a child's education and their socialisation and future career prospects and, without support, this situation will not improve as they get older. If misunderstood and unsupported, it can lead to a life of isolation and misery. Self-esteem and confidence are often affected too, through constant failure, bullying and disability discrimination. APD is a disability for life and a child with APD will become a teenager with APD, with a different set of problems to deal with. The teenager with APD will become an adult with APD, needing individually tailored accommodations and support in further education and seeking, finding and maintaining work. Also they may need support in navigating the benefits system, because even with qualifications, which some may not have, discrimination still exists amongst employers once you declare you have a disability that needs reasonable accommodations - no matter how capable the candidate might be with a little support which they are legally entitled to.

A person with APD needs to learn to live with APD, to get around it, but will still need lifelong support depending on its severity and their other co-existing conditions. Someone with very severe APD can be effectively incommunicative - unable to process speech at all, or reproduce it (one of the reasons it has been often misdiagnosed as autism). To meet the needs of each individual with APD, uniquely tailored accommodations are essential, in education and at work, in all areas of their lives. Adults can also acquire APD in later life and will also need specific support.

APD needs to be recognised and dealt with as the disability it truly is, and adequate help and support must be provided; it the legal right of every individual in the UK with APD.

FURTHER INFORMATION LINKS

http://apdsupportuk.yolasite.com/
http://www.gosh.nhs.uk/medical-information/search-medical-conditions/auditory-processing-disorder
http://www.nhs.uk/conditions/auditory-processing-disorder/Pages/Introduction.aspx
http://www.thebsa.org.uk/bsa-groups/group-apdi/
http://www.apduk.org.uk/

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Best wishes

Alyson Mountjoy