

Cynulliad Cenedlaethol Cymru | National Assembly for Wales  
Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and  
Education Committee

Blaenoriaethau ar gyfer y Pwyllgor Plant, Pobl Ifanc ac Addysg |  
Priorities for the Children, Young People and Education Committee

CYPE 16

Ymateb gan : Coeliac UK

Response from : Coeliac UK

**Question 1** – Within the remit set out above: what do you consider to be the priorities or issues that the Children, Young People and Education Committee should consider during the Fifth Assembly?

1. Medical needs in schools

**Question 2** – From the list of priorities or issues you have identified, what do you consider to be the key areas that should be considered during the next 12 months (please identify up to three areas or issues)? Please outline why these should be considered as key priorities.

1. Medical needs in schools:

1.1. **Legislative opportunity**

1.1.1. *‘I do believe that the Welsh Government has a unique opportunity here, given the unprecedented cross-party support that there is for this legislation, to actually make a difference to children and young people’s lives. The children and young people’s committee scrutinised the draft Bill and responded to the legislation, and one of the key concerns we had was that the draft Bill didn’t do enough to actually tie in the health service. We all know from our own casework that that is absolutely fundamental—the connection between health and education.’*

Lynn Neagle AM, June 28<sup>th</sup>, 2016

1.1.2. There is a need for a change in legislation in Wales to introduce

a statutory duty of care for children with medical needs in schools. This could be included within the newly proposed Additional Learning Needs (ALN) Framework.

1.1.3. The Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (see page 30 of the draft ALN Code of Practice). This is of concern to us and we ask the Committee to look at this again.

## 1.2. The difference between England and Wales

1.2.1. 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.

1.2.2. 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 make additional arrangements for supporting pupils at schools with medical conditions. This includes the creation of an individual health care plan for all children with medical needs which in the case of coeliac disease includes measures to limit the chances of a child with coeliac disease becoming ill at school or that they are excluded from school activities due to their condition. It also provides a framework that enables parents to respond where they feel this duty is not being met.

1.2.3. The legislation does not apply to schools in Wales. The current system in Wales therefore puts children with medical conditions, including those with coeliac disease, at an academic disadvantage in comparison to their peers in England and does not protect them to the same degree whilst they are at school. This is an inequity with which we feel the committee should be concerned.

## 1.3. Why an effective framework matters

- 1.3.1. Coeliac disease is a lifelong autoimmune 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.
- 1.3.2. 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. This can result in absence from school and can ultimately impact on learning. Strict adherence to the gluten-free diet is therefore essential at all times.
- 1.3.3. It is for this reason we are particularly concerned that there is little to no reference in current guidance 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 with their peers or taking part fully in school activities because of any perceived inconvenience caused by their requirement for gluten-free food.
- 1.3.4. We regularly receive enquiries from families of children whose attendance, attainment and overall educational experiences are compromised because of their condition and the lack of guaranteed support from the current framework. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.
- 1.3.5. Providing such support to children and young people with medical conditions to enable them to participate in all aspects of school life requires a co-ordinated effort. A framework of support for children with medical conditions, agreed between the school and parents to enable children to participate fully in the school day is vital to ensure effective care and learning in the

school environment.

1.3.6. We ask the Committee to consider the current situation and question whether there is a need to bring the rights, support and protection provided to children and young people living with coeliac disease in Wales in line with those in England.

1.3.7. There is currently a unique and rare opportunity to do this during this Government's legislative programme.

1.4. **Further notes:**

**Coeliac UK:**

1.4.1. 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. [www.coeliac.org.uk](http://www.coeliac.org.uk).

**1.4.2. What is gluten?**

1.4.3. 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](#) is available on the Coeliac UK website and you can view our school packs [here](#).