Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education Committee
Bil Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru)| Additional Learning Needs and Education Tribunal (Wales) Bill

ALN 25

Ymateb gan: Coeliac UK
Response from: Coeliac UK

1. **The general principles of the Additional Learning Needs and Education Tribunal (Wales) Bill and whether there is a need for legislation to deliver the Bill's stated policy objectives;**

   1.1. General principles

      1.1.1. Coeliac UK commends the Welsh Government's ambition in seeking legislation that is fit for purpose, is fair and that underpins the rights of children and crucially that guarantees equity of rights. We only ask that such equity is also extended to all children with medical needs and not just those with a disability as defined by the Equality Act (2010).

      1.1.2. We note that many of the issues raised by the bill with regard to ALN also apply to the existing situation for children with medical needs and it would appear strange to seek to redress this for one cohort of children and not another. To do so would surely send a message that children with medical needs are deemed less important than those with ALN.

      1.1.3. Coeliac UK is concerned by the failure to include medical needs in the proposed ALN Bill and fear that unless this is reversed, children with coeliac disease, as well as those with other medical conditions, will be put at unnecessary and unjustifiable risk.

      1.1.4. For children with coeliac disease the support required relates to access to gluten free food to enable adherence to the gluten free diet, the medical treatment for the disease.

      1.1.5. We would be happy to support the general principles of the bill with the caveat that it is necessary to include medical needs within it in order to safeguard the needs of children with medical conditions.

1.2. Whether there is a need for legislation

1.2.1. Coeliac UK believes it is necessary to reform the current framework for medical needs support in schools in order to provide clarity over the legal obligations and responsibilities of schools. We believe that the updating of the 2010 guidance document alone is insufficient to deliver the required improvements and consistency in care. In particular we note the disparity between the strength of provision in England compared to Wales. Section 100 of the Children's and Families Act 2014 states for example that 'The appropriate authority for a school to which this section applies *must* make arrangements for supporting pupils at the school with medical conditions'. This is in stark contrast to the voluntary, non-directive approach of the system in Wales.

1.2.2. Much work has gone into the reformulation and updating of the 2010 schools guidance document and this is to be welcomed. As has been noted, the existing guidance fails to deliver for children with medical needs and clearer, more accessible guidance is needed. However our concern is that as long as it remains purely voluntary and non-directive, it will ultimately remain inadequate.

2. Impact of inclusion into the statutory framework on schools who positively engage

2.1. It will provide assurance and protection to families, their staff and Local Authorities that they are doing as instructed and required by law.

2.2. It will provides clear expectations relating to the support that may be expected for all parties.

2.3. It will assist in dispute avoidance prior to the need for dispute resolution.

2.4. It lays down standards for investigation and improvement in cases where non-conformances arise.

3. Impact of a statutory duty on schools who do not engage

3.1. If no change, guidance will continue to be ignored by some and we will continue to fail in supporting children with medical needs whilst in education which will impact on educational outcomes as well as the health of children.

3.2. Currently, support is variable for children with coeliac disease and there is a clear lack of understanding both of the condition and the duties and support required of schools and staff. For children with coeliac disease it is essential to ensure that their condition is understood and that they are supported in school. This includes appropriate communication with school caterers to minimise the risk of cross contamination with gluten and taking reasonable measures and adjustments to ensure they are not excluded from school activities (such as cookery lessons and schools trips).

3.3. Where this fails, the implications for the child are significant. Symptoms can be severe and lead to missing school and impacting on learning. It will in turn have a negative impact on the health of this group of children, at an increased cost to the NHS.

3.4. Children, parents and healthcare professionals will continue to lack confidence that the right framework is in place if this is not addressed. Resolving disputes can take months and we hear from families whose children have been inadvertently given gluten containing food whilst at school, complaining of lengthy discussions with teachers and caterers to ensure the future provision of safe gluten free meals.

3.5. Children with coeliac disease are often obliged to take packed lunches into school and may be excluded from certain school activities involving food preparation or access to gluten free food. This can lead to them feeling stigmatised and impact upon their confidence and wellbeing.

4. **Any potential barriers to the implementation of the key provisions and whether the Bill takes account of them;**

4.1. We are concerned that the needs of children with medical conditions will be overlooked unless there is a duty on the face of the Bill.

5. **Unintended consequences arising from the Bill;**

5.1. The Equality Act (2010) defines some medical conditions as disabilities, meaning they would be included within the ALN framework. However a significant number of medical conditions fall outside of this definition and therefore children with long term but manageable (with the right risk analysis based approach) conditions could be excluded despite the clear case for additional support being required.

5.2. We are concerned for the potential for this Bill to lead to a two tier system in which children with defined ALN are given priority over those with medical needs when it comes to support in schools.

5.3. Coeliac UK also notes that whilst the ALN code is a statutory document, it signposts to non-statutory medical needs guidance which in itself provides no guarantee of support to the child. This could lead to significant confusion.

6. **Financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum)**

6.1. We would expect the Welsh Government to take appropriate measures to support inclusion of medical needs within the bill.

7. **Appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 5 of Part 1 of the Explanatory Memorandum).**

7.1. There may be a need for provision for third party contracts or secondary legislation to ensure medical needs of children are being met where the issue does not concern medicines management or training of medical or teaching staff but rather other duties of care within the school such as catering. This is particularly relevant where the condition falls outside of the Equality Act (2010) definition of disability, as is the case with coeliac disease.

8. **Additional comments on specific issues raised by the bill**

8.1. The provisions for collaboration and multi-agency working, and to what extent these are adequate;

8.1.1. Health services are mentioned throughout but not children with healthcare needs.

8.1.2. For conditions such as coeliac disease which is managed by strict adherence to the gluten free diet it is crucial that caterers are properly engaged in understanding the needs of the children and are equipped to make the necessary provision that will prevent unnecessary exclusion. It is therefore important to recognise other third parties needed to support children with medical needs in schools.

8.2. Whether there is enough clarity about the process for developing and maintaining Individual Development Plans (IDPs) and whose responsibility this will be;

8.2.1. Greater clarity is needed to distinguish between IDPs and IHPs and to define their relationship to each other.

8.3. **Proposed new arrangements for dispute resolution and avoidance. It would be helpful to the Committee if respondents could identify how the Bill could be amended to improve any aspects which they identify as inadequate.**

8.3.1. The proposed arrangements do not currently apply to medical needs. This is a failure as many of the issues the measures seek to address are equally relevant to children with medical needs. Where there is a dispute regarding support for a child with medical needs, it can often be a real challenge for parents and carers to find appropriate redress and the lack of a clear independent framework for resolving such disputes often results in an unnecessarily adversarial process.

8.3.2. Coeliac UK believes the inclusion of medical needs as part of the ALN framework would greatly improve the experience for parents and carers of children with coeliac disease and limit the need for resorting to unnecessary legal action. Again, we believe developments in England following the implementation of the ‘Children and families Act 2014’ show the benefits of a statutory duty in this respect. By having a clear duty and appropriate guidance, disputes can be anticipated and avoided prior to concerns escalating.

8.3.3. For children with coeliac disease the most important priority at school is ensuring they do not become ill as a result of being served food that contains gluten. School catering staff and commissioned catering services should have the knowledge to safely prepare gluten free meals to enable children with coeliac disease to have school dinners. In addition, it is important that children with coeliac disease are not excluded from activities because of their gluten free dietary requirements. There is guidance freely available on gluten free provision and management of coeliac disease from Coeliac UK.

8.3.4. Our concern however is that if there is no statutory requirement enabling children with coeliac disease to be included at school by supporting provision of gluten free meals, there will be no impetus for schools and associated catering staff and commissioned catering services to provide such support. In contrast, if there is a clear framework for children with medical needs, the responsibilities and requirements for caterers will be well defined, and make resolution simple.

9. Further notes:

9.1. Coeliac UK:

9.1.1. 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 65,000 Members across the UK and 3,000 in Wales. www.coeliac.org.uk.

9.2. Coeliac disease

9.2.1. Coeliac disease is a lifelong autoimmune disease caused by a reaction of the immune system to gluten – a protein found in wheat barley and rye. The disease can present at any age after introduction of gluten in the diet and so commonly presents in childhood. When someone with coeliac disease eats gluten, their immune system reacts abnormally, damaging the lining of the small intestine. Symptoms can include bloating, diarrhoea, nausea, wind, constipation, extreme tiredness, mouth ulcers, and faltering growth. The medical treatment for the condition is a strict gluten-free diet for life.

9.3. What is gluten?

9.3.1. 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 may also be present in foods that you may not expect, such as 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 is widely recognised as being expert in the Gluten Free diet and provides Gluten Free training and accreditation to the food industry. We also certify Gluten Free products with the Crossed Grain symbol. Coeliac UK has a variety of information and advice, available from www.coeliac.org.uk/food.