CEREBRA
Working wonders for children
with brain conditions

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23rd June 2025

Dear Buffy

Continence care support services for disabled children in Wales

Thank you for meeting with us on 22 May 2025. As requested, we are writing to highlight the issues raised at our meeting.

Cerebra is a Wales-based charity which operates throughout the UK nations and supports families of children with brain conditions. Our Legal Rights Service has received regular reports from families concerning difficulties in accessing fit-for-purpose continence care support services for their disabled children – and, in particular, in accessing appropriate continence containment products.

In 2023, we commissioned a research project to investigate families' concerns about continence provision, which was led by Luke Clements, Cerebra Professor of Law and Social Justice at the School of Law, Leeds University and culminated in a report published in February 2025.

Summary of the report's findings

The report[1] highlights the barriers families face in trying to access continence provision, including rigid restrictions on the number and type of products, poor quality and ill-fitting products and a lack of proper assessment and support.

The report describes the devastating physical, psychological and social impact of inadequate and discriminatory 'one size fits all' continence provision. It concludes that the harm being caused to disabled children who live with bladder and bowel difficulties amounts to a violation of their fundamental human rights – in terms of their right to education, to dignity, to inclusion and to freedom from degrading treatment.

The research[2] highlights, in particular, the traumatic school experiences of disabled children with bowel and bladder conditions: children desperate to be included but acutely self-conscious because of the rudimentary design of their highly obvious (often outsized) and poor quality containment products and

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[1] Clements L, Aiello A and Fullard, L Inaccessible, unacceptable and unaccountable: the provision of paediatric continence supplies in England, Wales and Scotland (Cerebra 2025).
[2] Ibid, paras 7.41 – 7.51.

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having to manage the devastating shame they experience, in terms of leakages, of smelling, of being bullied – and of being robbed of fundamentally important and unrecoverable childhood experiences.

Disabled children and their families are one of the most disadvantaged groups in the UK. Many parents also referred to the severe financial hardship they experience in having to pay for sufficient and suitable containment products and for the costs incurred as a result of the poor quality (and/or quantity) of products – of constantly having to wash clothing, bedding, carpets, furniture – and indeed repeatedly having to throw away bedding, clothing and much else.[3]

The report explains how the guidance currently in force in Wales is unfortunately contributing to the situation by failing to uphold equalities and human rights legislation.

Problems with the guidance in force in Wales

The current Welsh Government Circular WHC/2022/004, *Guidance for the care of children and young people with continence problems*[4] confirms that the Welsh Government has adopted guidance produced in 2021 by the charity Bladder and Bowel UK (BBUK) as the official guidance in Wales (which we refer to below as the '2021 Guidance').

Unfortunately, the Welsh Circular cited above contains an assertion that is self-evidently wrong, and the 2021 Guidance demonstrates a profound misunderstanding of the Welsh Government's obligations under the Equality Act 2010 and the Human Rights Act 1998, as explained below.

(i) Misunderstanding of the Equality Act 2010

The 2021 Guidance is underpinned by a straightforward misunderstanding of the requirements of the Equality Act 2010. It strongly, and repeatedly, suggests that unlawful discrimination occurs when a disabled child is treated more favourably than a child who is not disabled - for example, at page 13:

- to '*offer products for night time wetting to CYP [Children and Young People] who have a special need or disability could be considered discriminatory, as CYP who do not have additional needs are not provided with containment products for bedwetting'*;

and at page 17

- '*to provide containment products for night time wetting in children who are toilet trained in the day could be considered to be discriminatory and in breach*

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[3] Ibid paras 7.52 – 7.55.

[4] Please see paragraphs 3 and 11.

> *of the Equality Act 2010, as containment products are not provided for night time wetting to CYP who do not have additional needs'*.

This demonstrates a fundamental misunderstanding of the Government's equal treatment obligations. The Equality Act 2010 section 13(3) makes it absolutely clear that treating a disabled person more favourably than someone who is not disabled does not, in itself, constitute unlawful discrimination.

(ii) Blanket ban on provision of products to children under 5

The 2021 Guidance also states that no continence containment products can be provided to children under the age of five. In the absence of compelling reasons to justify this difference of treatment on grounds of age (and disability) such a policy constitutes discrimination contrary to Article 14 (in combination with Article 8) of the Human Rights Act 1998.

Disabled children are more likely to suffer from bladder and bowel difficulties than their non-disabled peers: many are incapable of achieving full continence and many will take considerably longer to achieve full continence than children who are not disabled. The research data suggests that from the age of 3 years onwards, the cohort of children who are bladder and bowel incontinent will contain an increasingly significant proportion of disabled children.

It follows that a rigid policy of restricting support to all children aged five and above is likely to have a disproportionate and adverse impact on disabled children.

Given the evidence of the profound (and persistent) harms experienced by disabled children who are bladder and/or bowel incontinent[5] and the impact on their families[6] it is difficult to (a) see how such a rigid policy can be justified and (b) understand why public bodies are unable to make reasonable adjustments to their policies by acknowledging the materially different challenges faced by disabled children.

(iii) Maximum limit of 4 pads per day

The 2021 Guidance imposes a maximum daily limit of four pads per person. It provides no research-based evidence that justifies this restriction. The survey responses set out in the report demonstrate the profound harm and indignities experienced by disabled children and their families due to the four pad per day limit. From a lay person's perspective, it is difficult to believe that such a limitation will be appropriate for all young people: people of very different sizes, constitutions, disabilities and illnesses.

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[5] Ibid paras 2.03 – 2.06 and Appendices 3 and 4.

[6] Ibid paras 7.52 - 7.60.

Indeed, Department of Health guidance issued in 2000 (in England) stated[7] that '[p]ads should be provided in quantities appropriate' to the individual's continence needs and that arbitrary ceilings should not be imposed, stating that:

> A few patients, such as those with copious diarrhoea, a bladder or bowel fistula and some people with learning difficulties have needs well above the average and will need large quantities of pads to provide adequate containment. It is not acceptable for people with faecal incontinence to be supplied with so few pads that they have to reuse the same pad after they have become soiled, as serious skin complications can develop.

And, in 2017, Welsh Government Circular WHC/2017/044 *Guidance for the care of children and young people with continence problems*[8] accepted that to impose a maximum of four pads per 24 hours was '*inconsistent with public law principles and a breach of children's' dignity*'; that it does '*not take into account the need for a full assessment'* and did not meet (among other things) its standard concerning '*dignified care'*.

Unfortunately the current Welsh Government Circular WHC/2022/004 *Guidance for the care of children and young people with continence problems,* wrongly states in paragraph 7 that the 2021 guidance contains the statement '*The number of products issued per 24 hours would normally not exceed four, but provision should meet assessed need*.' Unfortunately, this is incorrect. In fact, the 2021 guidance (please see page 6) simply imposes a maximum of four products a day: and this assertion is repeated on page 15 (first paragraph) and page 16 (second bullet point).

Unfortunately, this misalignment between the Circular and the Guidance has resulted in the Welsh Government inadvertently moving away from the rights respecting position of the 2017 Circular.

What we believe needs to be done

In January 2025, just before the publication of our report, BBUK issued a new version of its guidance. Unfortunately, the issues referred to above have not been fully addressed and we believe that the guidance requires further revision in order to ensure compliance with equalities and human rights legislation. Fortunately, we have engaged in discussions with BBUK, who have been very receptive to our concerns and are aiming to produce a revised version of the Guidance by the end of the summer.

In light of this, we would suggest that when it becomes available the Welsh Government should consider endorsing the forthcoming version of the BBUK guidance, providing of course that it is satisfied that it is compliant with the requirements of the Equality Act 2010 and the Human Rights Act 1998. Alternatively,

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[7] Ibid para 4.02.

[8] WHC/2017/044

if in due course the guidance remains unsatisfactory, we would welcome a commitment from the Welsh Government to develop its own fit-for-purpose guidance.

Our report contains compelling testimony from families describing the barriers they face in getting adequate continence provision. We have attached an account from a parent in Wales which we hope will help to convey the profound impact that inadequate and discriminatory provision is having on disabled children and their families (please see Appendix 1) as well as an audio recording of the transcript. As a children’s rights respecting nation, we hope that the Welsh Government will seize this opportunity to resolve the shortcomings of the current guidance and set a clear example for the rest of the UK.

Yours sincerely

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