Inaccessible, unacceptable and unaccountable: the provision of paediatric continence supplies in England, Wales and Scotland.

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L Clements, A Aiello and L Fullard (Cerebra February 2025).

Cerebra is a national charity helping children with brain conditions and their families to discover a better life together.
We work closely with our families to find out where help is most needed and then work with our university partners to fund the relevant research. Our research work across neurodevelopmental conditions gives us a unique perspective within the charity research sector.
Our aim is to provide research-driven, high-quality health and social care advice and support for the families of children with brain conditions from birth to the age of 16.

Legal Entitlements & Problem-Solving (LEaP) Project is an innovative problem-solving project that helps families of children with brain conditions cope with the legal barriers they face.

We listen to families and help them get the knowledge they need to access health, social care and other support services. We identify the common legal problems that prevent families getting access to services and we develop innovative ways of solving those problems. We aim to reach as many families as we can by sharing our solutions as widely as possible.

School of Law Leeds University Community Engagement is fundamental to the ethos of the School of Law at the University of Leeds. Students are given every encouragement and support to use their legal skills to benefit the local community. In doing this, students develop these skills and deepen their understanding of the role of the law in the real world: the central role of the law in fostering social justice. In furtherance of this aim the School supports (among other initiatives) a number of law clinics and the Cerebra LEaP project.

Parent and Carer Alliance C.I.C offers independent practical and emotional support for parents and carers. They have created a welcoming and safe community of families and are a source of reliable, factual, information from both national and local sources, as well as provide peer support. They inform and empower families through training and social events. They gather the lived experiences of families about their difficulties, and use this information to lobby all relevant parties, to ensure that positive changes are made.

CONTENTS

Overview

This research report concerns the way that the health services in England, Scotland and Wales respond to the continence care needs of disabled children. Its particular focus is on the provision of containment products (such as nappies, pads and ‘pull ups’). The research involved surveys of parents of disabled children, the making of freedom of information requests and website searches.

Approximately 900,000 children and young people suffer from bladder and bowel dysfunction. Disabled children are considerably more likely to experience incontinence related problems and to need continence containment products than their non-disabled peers. Such problems can be life threatening, excruciatingly painful, stigmatising, socially isolating, significantly impacting on their education, denying almost all normal childhood experiences and materially undermining their sense of self-worth.

Key Messages

- **The impact of inadequate provision:** Many of the distressing indignities described by respondents to the research surveys are of such severity as to engage fundamental human rights provisions: of disabled children experiencing conditions that are objectively degrading; of severe interferences with their private and family lives; of unlawful discrimination; and of inexcusable interruptions to their education (para 7.03).
- **Failure of accountability:** the research concludes that there has been a wholesale failure of accountability in relation to the commissioning of paediatric continence services in all three nations: that the absence of formal Governmental guidance has resulted in unacceptable variations as to what is, in practice, provided (para 7.19).
- The failure of accountability is particularly serious in England where over 85 per cent of the NHS commissioning bodies surveyed were unable to provide any information as to the paediatric continence services they had commissioned (para 7.20).
- **Discrimination:** The research finds that in most regions the criteria that are applied in practice, to determine a child’s eligibility for support (and the extent of that support) violate fundamental principles of dignity and are discriminatory (paras 7.23 - 7.39).
- **School impacts:** The research highlights 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 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 (paras 7.48 – 7.51).
- **Poverty:** Disabled children and their families are one of the most severely disadvantaged groups in the UK. Many parents 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 (para 7.52 – 7.55).

Action

- The research findings should act as an urgent wake up call to the three Governments to publish ‘fit-for-purpose’ guidance that requires in every region, the provision of dignified, accessible, non-discriminatory and properly resourced continence services for disabled children (para 7.22).

1. Introduction

1.01 This report concerns the way that the health services in England, Scotland and Wales respond to the continence care support needs of disabled children – with particular focus on the provision of continence containment products.[1] When referring to a child or children in this report, the reference is to a person under the age of 18.

1.02 Since its inception in 2013, the Cerebra Legal Entitlements & Problem-Solving (LEaP) Project has undertaken research based on the experiences of families with disabled children. The Cerebra in house research team listens to families and helps them get the knowledge they need to access health, social care and other support services. As part of this process the team identifies commonly occurring legal problems that prevent families getting access to services and, working with the School of Law at the University of Leeds, research is then undertaken with the aim of developing innovative ways of solving these problems.

1.03 From its outset, the Cerebra LEaP Project has received regular reports from families concerning the difficulties they have encountered in gaining access to fit-for-purpose continence care support services for their disabled children. The most pressing such concern families have identified has been the difficulty in accessing appropriate continence containment products. These have, for example, included concerns about their quality (leading to leakages and pad slippages); their quantity; the arbitrary and non-disability specific criteria by which eligibility is determined; and the restricted range of products available.

1.04 The Cerebra LEaP Project has, over the years, worked in various ways to tackle this problem: providing individual advice to parents; preparing template letters for families who encounter such problems;[2] publishing legal notes[3] and myth buster' guidance;[4] and by lobbying both NHS England and the Welsh Government for change.

1.05 Notwithstanding the individual successes/concessions achieved by this action, the number of families contacting the Cerebra LEaP Project with similar concerns has not abated – indeed it appears the situation in several parts of Britain is deteriorating.

1.06 Although approximately 900,000 children and young people suffer from bladder and bowel dysfunction,[5] of particular concern has been the realisation that in some English regions, no children's bladder and bowel continence services

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[1] Meaning products such as nappies, pull-ups, pants, pads, or bed protection products.

[2] Available at https://cerebra.org.uk/get-advice-support/legal-and-financial/template-letters/ accessed 16 January 2025.

[3] 'Digest of Opinions' Jinny's story (2013), available at https://cerebra.org.uk/wp-content/uploads/2019/07/2013-Summer-Autumn-Digest-FINAL1.pdf accessed 16 January 2025.

[4] 'Myth buster' (2019) resource, available at https://cerebra.org.uk/wp-content/uploads/2019/12/mythbuster-continence-june19-low-res.pdf accessed 16 January 2025.

[5] At https://www.england.nhs.uk/publication/excellence-in-continence-care/ accessed 10 November 2024.

have been commissioned[6] and, at the time writing this report, in at least one region there is an active proposal to close an existing service.[7]

1.07 In consequence it was decided in 2023 that specific research should be undertaken concerning the prevalence, causes and impact on families of restricted access to continence containment products.

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[6] Bladder & Bowel UK 'Guidance for the provision of continence containment products to children and young people. A consensus document' (2021) p. 8 at https://www.bbuk.org.uk/wp-content/uploads/2021/06/Guidance-for-the-provision-of-continence-containment-products-to-children-2021.pdf accessed 10 November 2024.

[7] Letter 26 June 2024 'Cornwall County/Together for Families' to Parents(s)/Guardians announcing that from 1st April 2025 it will no longer be providing continence products.

2. Disabled children and continence care: an overview

2.01 Disabled children and their families are one of the most severely disadvantaged groups in the UK.[8] 'The association between poverty and child disability indicates that disabled children are significantly more likely to live under conditions that have been shown to impede development, educational attainment and adjustment, and increase the risk of poor health, additional impairment and social exclusion'.[9]

2.02 Each disabled child is unique, as are the clusters of disability related challenges that they and their family's encounter. One such challenge concerns their difficulty in accessing appropriate care and support for bowel and bladder problems. As this report notes, disabled children are considerably more likely to experience such problems than non-disabled children – problems that can be life threatening, excruciatingly painful, stigmatising, socially isolating, significantly impacting on their education, denying almost all normal childhood experiences and materially undermining their sense of self-worth. These are concerns that engage some of the most fundamental aspects of human dignity. For a state (particularly a wealthy western state) to make inadequate arrangements to protect children and their families from such harms and indignities must be a matter of shame which this report argues can be articulated in the language of the law, notably the law concerned with non-discrimination and human rights.

2.03 Incontinence was one of the most frequently reported long-term health conditions found in the 6,775 adults who died in 2018, 2019 or 2020 by the 2020 Learning Disabilities Mortality Review.[10]

2.04 Incontinence is major cause of ill health and affects disabled children disproportionately: children with Spina bifida/spinal problems,[11] with Down's syndrome,[12] children with Anorectal malformations, children with Hirschsprung disease, cerebral palsy,[13] learning disabilities, acquired brain and spinal cord

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[8] See generally S Broach and L Clements *Disabled Children : a legal handbook* (Legal Action 3rd 2020) paras 1.31 – 1.55 for a critical overview of the multiple levels of disadvantage such families experience.

[9] Department for Work and Pensions*, Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013; and Contact a Family *Counting the Costs* 2014 para 3.2.9..

[10] University of Bristol Norah Fry Centre for Disability Studies *Learning Disabilities Mortality Review (LeDeR) programme Annual Report* 2020, p25. at https://www.bristol.ac.uk/sps/leder/uob-2015-21/annual-reports/ accessed 29 October 2024 and see also A Hill 'Gross failure in man's care led to death from constipation' 8 February 2018 at https://www.theguardian.com/uk-news/2018/feb/08/gross-failure-in-mans-care-led-to-death-from-constipation accessed 1 November 2024.

[11] K Smith, A Neville-Jan, K A Freeman, E Adams, S Mizokawa, B J Dudgeon, M J Merkens and W O Walker 'The effectiveness of bowel and bladder interventions in children
with spina bifida' Developmental Medicine & Child Neurology (2016) 58: 979–988.

[12] J Rogers, and M Patricolo 'Addressing continence in children with disabilities' *Nursing Times*; (2014) 110: 43, 22-24 and J A Hicks, C Carson, P S Malone 'Is there an association between functional bladder outlet obstruction and Down's syndrome?' Journal of Paediatric Urology (2007) 3(5):369-374.

[13] A J Wright, O Fletcher, D Scrutton, G Baird 'Bladder and bowel continence in bilateral cerebral palsy: A population study' Journal of Pediatric Urology 12(6) Dec 2016, 383.

injuries, transverse myelitis,[14] autism,[15] ADHD[16] and many more conditions.[17] Research suggests that urinary incontinence in adolescence results in increased adverse psychosocial outcomes such as poor self-image, depressive symptoms, peer victimisation, and problems with peer relationships.[18] These difficulties are, it appears, particularly acute in school environments where research suggests that young people with continence problems are at higher risk of academic underachievement and of experiencing (among other things) feelings of rejection, loss of self-esteem, social isolation, bullying and school exclusion.[19]

2.05 For many families with disabled children living on low incomes, in addition to the ‘loss of control’ they experience when encountering dysfunctional systems relating to the provision of continence containment product services, the financial impact of having to self-fund products of this kind[20] drives then into greater poverty.

2.06 People of all ages with autism[21] and/or learning disabilities have much higher rates of constipation than those without learning disabilities.[22] Long-term constipation is associated with urinary and faecal incontinence and can increase, embarrassment, social isolation and anxiety.[23] Although constipation is considered to be a ‘treatable medical condition’ it is potentially very

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[14] Pouard T ‘Constipation in people with learning disabilities: prevalence and impact’ (2023) Nursing Times [online]; 119: 4 13 March, 2023 at https://www.nursingtimes.net/roles/learning-disability-nurses/constipation-in-people-with-learning-disabilities-prevalence-and-impact-13-03-2023/ (accessed 8 October 20-24.

[15] J Niemczyk, C Wagner and A von Gontard ‘Incontinence in autism spectrum disorder: a systematic review’ European Child & Adolescent Psychiatry (2018) 27:1523–1537.

[16] A von Gontard, J Hussong, S S Yang, J Chase, I Franco and A Wright ‘Neurodevelopmental disorders and incontinence in children and adolescents: Attention-deficit/hyperactivity disorder, autism spectrum disorder, and intellectual disability—A consensus document of the International Children's Continence Society’ Neurology Urodynamics 41(1) January 2022, 102-114.

[17] Mosiello G, Safder S, Marshall D, Rolle U, and Benninga, M A. ‘Neurogenic Bowel Dysfunction in Children and Adolescents Journal of Clinical Medicine’ (2021) April 10(8), 1669.

[18] Grzeda M T, Heron J, von Gontard A, and Joinson C ‘Effects of urinary incontinence on psychosocial outcomes in adolescence’ (2017) European Child and Adolescent Psychiatry 26, 649.

[19] K Whale, H Cramer and C Joinson ‘Left behind and left out: The impact of the school environment on young people with continence problems *British Journal of Health Psychology (2018), 23, 253–277*

[20] Bladder and Bowel UK ‘Guidance for the provision of continence containment products to children and young people A consensus document’ (2021) BBUK para 1.2 at https://www.bbuk.org.uk/wp-content/uploads/2021/06/Guidance-for-the-provision-of-continence-containment-products-to-children-2021.pdf accessed 12 November 2024.

[21] C Maslen, R Hodge, K Tie, R Laugharne, K Lamb and R Shankar *Constipation in autistic people and people with learning disabilities* British Journal of General Practice 2022; 72 (720): 348-351

[22] Public Health England (PHE) Guidance: Constipation: making reasonable adjustments (2016) at https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities/constipation-making-reasonable-adjustments accessed 28 October 2024.

[23] Public Health England (PHE) Guidance: Constipation: making reasonable adjustments (2016) at https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities/constipation-making-reasonable-adjustments accessed 28 October 2024.

dangerous, resulting in serious illness and death.[24] It is a condition that can be exacerbated by inappropriate or poor continence care arrangements.[25]

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[24] Public Health England (PHE) Guidance: Constipation: making reasonable adjustments (2016) at https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities/constipation-making-reasonable-adjustments accessed 28 October 2024; Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, and Rus L *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report* (2013) Norah Fry Research Centre at https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf accessed 29 October 2024; and NHS *Learning Disability Mortality Review (LeDeR) Programme: Action from Learning* (2019) at https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf accessed 28 October 2024.

[25] Arnaud M J 'Mild dehydration: a risk factor of constipation?' European Journal of Clinical Nutrition (2003) December 57 Supplement 2: 88-95.

3. The legal context

The National Health Service Acts

3.01 The Governments in England, Scotland and Wales are subject to an overarching duty to continue the promotion of a comprehensive health service in their nations, by virtue of the National Health Service (NHS) Act 2006, the NHS (Wales) Act 2006 and the NHS (Scotland) Act 1978. These statutes are collectively referred to below as the 'NHS Acts'. In each nation the healthcare duties imposed by these Acts have, in large measure, been delegated: in England to Integrated Care Boards (ICBs) and in Scotland and Wales to Health Boards (HBs).

3.02 The primary duty created by the NHS Acts, is the duty on the Governments to continue the promotion of a comprehensive health service designed to secure improvement in (among other things) physical and mental health and the prevention, diagnosis and treatment of illness.

3.03 The duty is considered to be a weak one – in essence it requires the Governments to use their 'best endeavours'[26] to achieve 'comprehensiveness'. This does not, however, mean that the courts will not intervene in appropriate situations – for example where there is evidence that the responsible body has abandoned this aim or, in relation to a mainstream or 'core' service, that it lacks a rational plan[27] to enable it to achieve this aim. In England the situation is, however, otherwise in relation to care and support needs identified as necessary in a disabled child's Education Health Care (EHC) Plan (Section G). In such cases the duty is immediate and absolute. [28]

3.04 Certain healthcare services have come to be considered 'core' functions for which the courts will 'more anxiously scrutinise'[29] assertions by Governments that they are using their 'best endeavours'. It has been suggested that core healthcare functions would include, for example, primary healthcare support,[30] an accident and emergency service[31] and end of life palliative care.[32] In a civilised country like the UK it is strongly arguable that the provision of adequate continence care for a disabled child is not only a basic humane

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[26] *R v North and East Devon Health Authority ex p Coughlan* [1999] EWCA Civ 1871; [2000] 2 WLR 622; *R(L) v Hampshire County Council* [2024] EWHC 1928 (Admin) at [42].

[27] See for example, *R (Rogers) v Swindon NHS PCT* [2006] EWCA CIV 392, and The Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health (Art. 12) (11 August 2000) E/C.12/2000/4 para 43.

[28] *R (A) v North Central London Integrated Care Board* [2024] EWHC 2682 (Admin).

[29] *R (Daly) v Secretary of State for the Home Department* [2001] UKHL 26.

[30] Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health (Art. 12) (11 August 2000) E/C.12/2000/4 para 43(a). The Committee (at para 13 footnote 9) explains, that '*primary health care* typically deals with common and relatively minor illnesses and is provided by health professionals and/or generally trained doctors working within the community at relatively low cost'.

[31] See for example, T W Burkholder, K Hill and E J Calvello Hynes 'Developing emergency care systems: a human rights-based approach' Bulletin of the World Health Organization (2019) June 97(9): 612–619.

[32] See for example, L Gwyther, F Brennan and R Harding 'Developing emergency care systems: a human rights-based approach' Journal of Pain and Symptom Management 38(5) November 2009, 767-774 – an argument that may have additional force in states that criminalise all forms of assisted suicide.

concern in order ‘to ameliorate and compensate’ for their disabilities but also an example of such a ‘core’ obligation of the state.[33]

3.05 What appears to be a broadly accepted ‘core healthcare’ principle is that any form of healthcare provided by the state should be available on a ‘non-discriminatory basis, especially for vulnerable or marginalised groups’.[34]

3.06 There is no explicit duty in the NHS Acts (or in regulations thereto) requiring Health Bodies to provide continence containment products. In England and Wales, the relevant Government guidance as to what products can be prescribed by health professionals (the ‘Drug Tariff’) makes it clear that its provisions do not apply to continence containment products.[35] In contrast, the Scottish Drug Tariff does provide for the prescribing of a limited range of continence containment products.[36]

3.07 In practice, state funded continence containment products are provided in almost all regions within the three nations – most particularly for older people. The demands of good administration (if none other) would suggest that detailed guidance should be issued by the Governments to ensure that this support is provided in an appropriate, efficient and equitable way. However, as we outline in the chapter that follows, very limited Government guidance has been issued concerning the provision of continence containment products and, objectively, no current guidance can be considered ‘fit-for-purpose’.

The NHS Constitution

3.08 The NHS Constitution (first published in 2009[37]) establishes the principles and values of the NHS in England. It is a document to which the Government must have regard when exercising functions in relation to the health service.[38] NHS England[39] and every ICB[40] are required, when exercising of their functions, to ‘act with a view to securing that health services are provided in a way which promotes the NHS Constitution’.

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[33] *Price v UK* (2001) 34 EHRR 1285 and see also para 3.24 below.

[34] Committee on Economic, Social and Cultural Rights, ‘General Comment No. 14: The right to the highest attainable standard of health (Art. 12) (11 August 2000) E/C.12/2000/4 para 43(a) at https://www.refworld.org/pdfid/4538838d0.pdf accessed 10 November 2024; J Tasioulas The Minimum Core of the Human Right to Health Research Paper World Bank October 2017p.10; and see also Principle One of the NHS Constitution considered at para 3.09 below.

[35] NHS Business Services Authority: NHS England and Wales Electronic Drugs Tariff (2024) Part IXB (Incontinence appliances) para 3 at https://www.drugtariff.nhsbsa.nhs.uk/#/00867990-DC/DC00867854/Part%20IXB%20-%20Incontinence%20Appliances accessed 10 November 2024.

[36] Public Health Scotland ‘Scottish Drug Tariff: Part 5 incontinence products’ at https://publichealthscotland.scot/media/26671/2024-11-sdt-part-5.pdf accessed 10 November 2024.

[37] Health Act 2009, section 1.

[38] Section 1B NHS Act 2006.

[39] Section 13C NHS Act 2006.

[40] Section 14Z32 NHS Act 2006.

3.09 Of particular relevance, in the context of this report, is its First Principle:[41]

> **Principle 1**
> The NHS provides a comprehensive service, available to all. It is available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status. The service is designed to improve, prevent, diagnose and treat both physical and mental health problems with equal regard. It has a duty to each and every individual that it serves and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.

Equality Act 2010

3.10 The Equality Act 2010 provides legal protection for anyone who is treated adversely because of a protected characteristic – which includes disability and age. Section 6 of the Act states that a person has a disability if: (a) they have a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Direct discrimination

3.11 Section 13 of the Act defines the concept of 'direct discrimination' – essentially discrimination that happens when someone is treated unfairly because of their protected characteristic – i.e. discrimination against a particular individual and for which the adverse treatment is explicitly linked to their protected characteristic. Where the protected characteristic is based on the persons sex or race, the grounds for justifying the adverse treatment are severely limited. However, where the protected characteristic is 'age' the Act permits a greater range of justifications[42] and in relation to 'goods and services' the Act provides no protection for discrimination experienced by 'persons who have not attained the age of 18.[43]

3.12 Where the protected characteristic is disability section 13(3) makes it clear that it is not discrimination simply because a person treats the disabled person more favourably than someone who is not disabled.

Indirect Discrimination and the Equality Act

3.13 Indirect discrimination[44] arises when an apparently neutral provision, criterion or practice applied by (for example) a public body, puts individuals with a

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[41] Principle One of the updated version of the Constitution as at November 2024 at https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england accessed 11 November 2024.

[42] Namely, that it is 'a proportionate means of achieving a legitimate aim' – section 13(2) Equality Act 2010.

[43] Section 28(1) and 31(2) Equality Act 2010.

[44] Equality Act 2010 s13.

particular protected characteristic (e.g. disability or age) at a disadvantage compared with others (section 19).

3.14 Indirect discrimination due to a person's age or disability is capable of being justified if it is a 'proportionate means of achieving a legitimate aim'.

Duty to make reasonable adjustments

3.15 Section 20 of the 2010 Act imposes a duty on public bodies, service providers and others to make reasonable adjustments when a provision, criterion or practice that they apply puts a disabled person at a substantial disadvantage in comparison with persons who are not disabled. In such cases the entity is required to take such steps as it is reasonable to avoid the disadvantage.

Public Sector Equality Duty

3.16 Section 149 Equality Act 2010 contains what is referred to as the Public Sector Equality Duty (PSED). This requires public authorities to have (among other things) 'due regard to the need' to eliminate discrimination, to advance equality of opportunity between 'persons who share a relevant protected characteristic and persons who do not share it'.

3.17 When developing, applying or reviewing a policy or practice, a public body must be able to demonstrate that it has had due regard to the requirements of section 149 (a process commonly referred to as undertaking an 'Equality Impact Assessment'). In *R (Brown) v Secretary of State for Work and Pensions,*[45] the court highlighted various principles[46] concerning the nature of the duty, namely that:

1. It is a general obligation. The duty is 'broad and wide ranging' (para 35) and arises in many routine situations, essentially whenever a public body is exercising a public function, including an exercise of judgment that might affect disabled people.[47]
2. Consideration is required before a decision is made. The consideration of the potential impact of the decision must take place 'before and at the time that a particular policy that will or might affect disabled people is being considered by the public authority in question'.
3. The duty is a substantial one. It is a duty of 'substance' that must be exercised 'with rigour and with an open mind' (para 92).
4. The duty is non-delegable.
5. It is a continuing duty.
6. It is a 'duty of record'. Public authorities must keep an adequate record showing that they had actually considered their disability equality duties and pondered relevant questions.

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[45] [2008] EWHC 3158 (Admin) at [84]–[96].

[46] Equality and Human Rights Commission *Technical Guidance on the Public Sector Equality Duty* (EHRC 2014).

[47] See also *Pieretti v Enfield LBC* [2010] EWCA Civ 1104.

3.18 Technical Guidance issued by the Equality and Human Rights Commission addresses the use of criteria to guide decision making in individual cases. It explains that the use of criteria does not remove the responsibility of the decision-maker to have due regard to the requirements of section 149. In the context of this report, criteria of this kind would include guidance adopted or formally endorsed by a public body albeit drafted by a body that is not generally considered to be a public body – for example a charity.

3.19 If there is evidence that decisions taken by the public body 'will have a detrimental impact upon or be disadvantageous to' those protected under the Equality Act 2010, the Technical Guidance states that 'the body will need to consider whether to review the policy'.[48]

The Human Rights Act 1998

3.20 Section 6(1) of the 1998 Act makes it unlawful for a public authority to act in a way which is incompatible with (among others) Articles 3, 8 and 14 of the European Convention on Human Rights (ECHR) and Article 2 of its First Protocol.

Article 3: degrading treatment

3.21 Article 3 is primarily negative in its scope – requiring states to refrain from subjecting anyone to torture, inhuman or degrading treatment. It has, however, been held to place a positive obligation on states to take reasonable measures to ensure that no one is subjected to such treatment: that, for example, the courts and social services are obliged to use their powers to protect children[49] and 'vulnerable adults'[50] from abuse.

3.22 The European Court of Human Rights has emphasised that for treatment to be 'degrading' it must reach a minimum threshold of severity,[51] although it has indicated that this may be significantly lower for disabled[52] and elderly people.[53] It has also made clear that a violation of Article 3 can take place, even where there was no positive intention on the part of the state to humiliate or debase the individual.[54]

3.23 *Đorðevic´ v Croatia*[55] concerned the harassment by school children of an adult with learning disabilities (Dalibor Đorðevic´) and his mother with whom he lived. The police and the social care authorities were aware of this ill-treatment but took no effective action. The court held that for a positive obligation to arise under Article 3, it had to be established that: 1) the authorities knew or ought to have known at the time of the existence of a real and immediate risk of ill-treatment of an identified individual; and 2) that the authorities failed to take

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[48] Paras 5.46 – 5.50.

[49] *Z and others v UK* (2002) 34 EHRR 97.

[50] *In re F (adult: court's jurisdiction)* [2000] 3 WLR 1740.

[51] *Costello-Roberts v UK* (1993) 19 EHRR 112.

[52] *Price v UK* (2001) 34 EHRR 1285.

[53] See *Papon v France* [2001] Crim LR 917, an inadmissibility decision.

[54] *D.G. v. Poland* European Court of Human Rights 12 February 2013 Application no. 45705/07 para 177 and *Price v UK* (2001) 34 EHRR 1285.

[55] *Đorðevic´ v Croatia* Application, no 41526/10, 24 July 2012.

measures within the scope of their powers which, judged reasonably, might have been expected to avoid that risk. Given the facts and the finding by the court that ‘no serious attempt was made to assess the true nature of the situation complained of ... the lack of any true involvement of the social services ... [and that] no counselling has been provided to the [learning disabled] applicant’, it found a violation of Article 3.

3.24 *Price v UK*[56] concerned a thalidomide-impaired applicant who in the course of debt recovery proceedings refused to answer questions put to her and was in consequence committed to prison for seven days for contempt of court. She alleged that she suffered degrading treatment as a result of the prison’s inadequate facilities, but the UK government argued that any discomfort she experienced had not reached the minimum level of severity required by Article 3. The court, however, considered that the threshold depended ‘on all the circumstances of the case, such as the duration of the treatment, its physical and mental effects and, in some cases, the sex, age and state of health of the victim’, and after a thorough review it concluded:

> ... that to detain a severely disabled person in conditions where she is dangerously cold, risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment contrary to Article 3.

3.25 Of particular interest is the concurring opinion of Judge Greve, in which she stated:

> It is obvious that restraining any non-disabled person to the applicant’s level of ability to move and assist herself, for even a limited period of time, would amount to inhuman and degrading treatment – possibly torture. In a civilised country like the United Kingdom, society considers it not only appropriate but a basic humane concern to try to ameliorate and compensate for the disabilities faced by a person in the applicant’s situation. In my opinion, these compensatory measures come to form part of the disabled person’s bodily integrity.

3.26 In *D.G. v. Poland*[57] the European Court of Human Rights considered the conditions of detention of a paraplegic and incontinent prisoner and held that these constituted a violation of his rights under Article 3, stating:

> where he does not have an unlimited and continuous supply of incontinence pads and catheters and unrestricted access to a shower, where he is left in the hands of his cellmates for the necessary assistance, and where he is unable to keep clean without the greatest of difficulty, reaches the threshold of severity required under Article 3 of the Convention and constitutes degrading and inhuman treatment contrary to that provision.[58]

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[56] *Price v UK* (2001) 34 EHRR 1285.

[57] European Court of Human Rights 12 February 2013 Application no. 45705/07 at https://hudoc.echr.coe.int/fre?i=001-116410 accessed 29 October 2024.

[58] Ibid at para 177.

Article 8: private and family life

3.27 Article 8 of the Convention protects the rights of individuals to respect for their private and family life, their home and correspondence. Any state sanctioned interference with this right must (among other things) be strictly necessary and pursue a legitimate aim (for example the protection of a child). The 'reach' of Article 8 is far greater than that of Article 3 and in many instances, Article 8 acts as a backstop for allegations concerning ill-treatment that are not sufficiently serious to reach a minimum threshold of severity for Article 3. By way of example, in the case of *Đorđevic´ v Croatia*[59] (considered above) although the Court found a violation of Article 3 in relation to the ill-treatment to which Dalibor Đorđevic´ was subjected, it found that the trauma his mother had experienced (in witnessing her son's ill-treatment) did not reach a minimum threshold of severity for Article 3, but nevertheless constituted a violation of her right to respect for her private and family life under Article 8.

3.28 The Strasbourg Court has given the notion 'private' life an expansive interpretation: one that it encompasses a 'person's physical and psychological integrity' for which respect is due in order to 'ensure the development, without outside interference, of the personality of each individual in his relations with other human beings'.[60] In a number of judgments concerning Article 8 rights it has asserted that the 'very essence of the Convention is respect for human dignity and human freedom' and it is in this context 'that notions of the quality of life take on significance.[61]

3.29 Article 8 is often considered the ECHR Article that places the most significant positive obligations on states. This requirement arises from the phrasing of the duty: not being to 'refrain from interfering' but an obligation to 'respect'. In *Marckx v Belgium* (1979)[62] the court held that the right, although 'essentially' that of protecting the individual against arbitrary interference by the public authorities – did 'not merely compel the State to abstain from such interference: in addition to this primarily negative undertaking, there may be positive obligations' which meant that 'when the State determines in its domestic legal system the regime … it must act in a manner calculated to allow those concerned to lead a normal family life.'

3.30 The Strasbourg Court considers that the positive obligation may require states to have a formal procedure by which the proportionality of the interference is assessed – i.e. a 'fair process'.[63] In many situations, this will require state regulation (or guidance) as to procedures that must be followed – particularly where there is potential for significant harm and where there is compelling evidence that current domestic arrangements are discriminatory.

3.31 In *McDonald v UK* (2014)[64] the Strasbourg Court accepted that Article 8 could be (and was in this case) engaged in relation to a complaint that concerned 'public funding to facilitate the mobility and quality of life of disabled applicants'. The case concerned an applicant who was continent and who defined her

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[59] Application no 41526/10, (2012) 15 CCLR 657.

[60] *Botta v Italy* (1998) 153/1996/772/973 24th February 1998.

[61] *Đorđevic´ v Croatia* Application, no 41526/10, 24 July 2012 para 152 and *Pretty v. UK*, no. 2346/02, 29 April 2002 para 65.

[62] Application no. 6833/74 13th June 1979 para 31; (1979-80) 2 E.H.R.R. 330.

[63] *McMichael v UK* 20 E.H.R.R. 205 (1995).

[64] Application No. 4241/12 20 May 2014.

needs as having help to access her commode at night. Her local authority refused to provide this support, suggesting instead that she use continence pads at night (to which she objected). The court considered that these facts were ‘capable of having an impact on her enjoyment of her right to respect for private life’ and so fell within the scope of Article 8. Nevertheless, the court considered that the domestic courts had undertaken an acceptable proportionality review – and accordingly that in reliance of the leeway given to domestic courts on such issues, determined that it should not interfere with the domestic judgment.

3.32 In the context of the current research, a relevant question is whether the court would have found a violation of the ECHR if the local authority had decided to provide no help at all (i.e. no continence pads or help to reach her commode).

3.33 In *R (Bernard) v Enfield London Borough Council*[65] the local authority failed to provide a disabled and doubly incontinent applicant (a mother of six children) with suitably adapted accommodation such that she suffered the humiliation of constantly defecating and urinating in her clothing, as she was unable to reach the toilet. The court held that this amounted to a clear cut interference with her right to respect for her private and family life. However, in relation to the argument that this also constituted a violation of Article 3, the judge held that this was ‘finely balanced’ – noting that ‘[d]eplorable though the conditions were ... I do not consider that they crossed the necessary threshold of severity so as to amount to a breach of the claimants' rights under Article 3’ (para 31).[66]

3.34 In this case, the authority was under a duty to provide suitable support to meet the applicant’s needs (in this case an accessible toilet). In the context of the current research, which concerns the provision of continence containment products, the question is whether such a failure would have amounted to a violation of the convention if there had been no such legal duty?

3.35 A 2009 Local Government Ombudsman report[67] concerned a mother who was living in accommodation that had no accessible bathing facility for two of her children – both of whom had profound impairments and were bladder and bowel incontinent. In relation to one of the children the report states that ‘he was aware of his body odour and would ask carers if he smells’ and that not infrequently he had faeces ‘spread across his body’. Due to the lack of accessible bathing his mother had ‘no option but to hose him down in the back garden, sometimes in the middle of the night’. Despite his school contacting the Children’s Disability Team, expressing concern that the problems were affecting his school life and his developing a deteriorating rash because he could not bathe regularly, the authority not only offered no suitable support, it also advised the mother that it considered her actions (in hosing her son) ‘abusive’ that it ‘must no longer happen’.

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[65] [2002] EWHC 2282 (Admin).

[66] The Supreme Court in *R (McDonald) v Royal Borough of Kensington and Chelsea* [2011] UKSC 33 para 17 used the severe experiences of the applicant in this case (ie borderline Article 3) to justify its rejection of Elaine McDonald’s claim: as Carr observes ‘[s]o the extreme case is deployed to defeat the instant case but simultaneously overlooks the importance of the mundane - H Carr ‘Legal technology in an age of austerity: documentation, 'functional' incontinence’ and the problem of dignity’ in D Cowan and D Wincott (eds) *Exploring the 'Legal' in Socio-Legal Studies* Springer (2019).p220

[67] Complaint no 07C03887 against Bury MBC, 14 October 2009.

3.36 In a strongly worded report, the Ombudsman described the council's actions as 'institutionalised indifference – not only to the boys' needs and their mother's plight but to the Council's duties and responsibilities' demonstrating 'breathtaking insensitivity' to a mother whose parenting skills and her commitment to care for her sons has never been in question'. The Ombudsman did not articulate her finding in the language of human rights – but (as with the *Bernard* decision above) the question that arises in the context of the current research, is whether the failure of the local authority in this case would have been acceptable if there had been no statutory duty to assess and meet the bathing needs of the disabled children?

Protocol 1 Article 2 ~ education

3.37 Article 2 of the First Protocol to the ECHR guarantees the right of children to access educational institutions provided by the state.[68] *Çam v. Turkey* (2016)[69] concerned a student who was refused entry into a school, because she was blind. The Strasbourg Court, in its judgment, acknowledged that national Governments were generally best placed to decide on what 'reasonable adjustments' were appropriate in such cases, but then cautioned (para 67):

> that it is important for the States to be particularly careful in making their choices in this sphere, having regard to the impact of the latter on children with disabilities, whose particular vulnerability cannot be overlooked. It consequently considers that discrimination on grounds of disability also covers refusal to make reasonable accommodation.

3.38 The High Court case of *R (ZB & DB) Croydon LBC and South West London ICB*[70] concerned the failure of the local authority to provide adequate school transport for two disabled children. It was argued that this amounted to a violation of their rights under Protocol 1 Article 2, and the court agreed.

3.39 In reaching his decision the judge referred to earlier cases where the courts had held that:

- 'although the Article 2 of Protocol 1 right is intended to guarantee fair and non-discriminatory access to' education, it is a 'weak right', and whether or not it is actually violated will depend on 'the specific facts of the case: have the authorities of the state acted so as to deny to a pupil effective access to such educational facilities as the state provides for such pupils?'[71] and
- 'the denial of education under [Article 2 of Protocol 1] can arise in a variety of ways' including 'a failure to take steps to provide education when the [responsible authority] is aware of the absence of the pupil from any form of education'. That it is 'at least arguable that an authority with the responsibility for providing

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[68] *Belgian Linguistics Case (No.1)* 1 EHRR 241 (1967) and see *Ingrid Jordebo Foundation of Christian Schools and Jordebo*, DR 51/125.

[69] *Çam v. Turkey* Applic No. 51500/08 February 24, 2016 and see also *Enver Şahin v Turkey* (2018) 30 January Application No. 23065/12 where the Court found a violation of Article 14 with Article 2 of Protocol No. 1 on the ground that there was no possibility of suitable adjustments being made to enable the applicant (who was paraplegic) to enter university buildings for the purpose of his studies. See also *Stoian v. Romania* Application No. 289/14 25 June 2019.

[70] [2023] EWHC 489 (Admin) 7 March 2023.

[71] Citing *A v Head Teacher and Governors of Lord Grey School* [2006] 2 AC 363, para 24.

education, if it knows that a pupil is not receiving it and engages in a completely ineffectual attempt to provide it, is in breach of the provision.'[72]

Article 14: discrimination

3.40 Article 14 requires that States secure the rights of individuals under the Convention (and its protocols) without discrimination on any ground – for example, disability[73] or age.[74]

3.41 The Article 14 right is limited to discriminatory treatment that individuals' experience in relation to their 'Convention rights' – such as their right not to be subjected to degrading treatment under Article 3 or their right to have their private and lives respected under Article 8. Where a *prima facie* case of discrimination contrary to Article 14 is made out, the onus of explaining or justifying this state of affairs, shifts to the State.

3.42 In relation to claims of unlawful discrimination, domestic courts will generally only consider compliance with Article 14 if, for any reason, the 2010 Act has failed to adequately address the impugned behaviour. In the context of this report, this could arise because of exclusory provisions within the 2010 Act (eg relating to goods and services for children - see para 3.11 above) or due to the discrimination engaging what is known as the *Thlimmenos* principle.

3.43 In *Thlimmenos v Greece* (2000),[75] the Court held that the right 'not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different'.[76]

3.44 The *Thlimmenos* principle was applied by the Court of Appeal in *Gorry v. Wiltshire Council and others.*[77] The case concerned the so called 'bedroom tax' that penalised families that were in receipt of housing benefit if their house had more bedrooms than deemed necessary by the regulations. These stipulated (among other things) that only one room was required for two children under 10 years of age – on the basis that it would be reasonable for them to sleep in the same room. However, the Gorry sisters, although under 10, had impairments which meant that it was inappropriate for them to share a bedroom. The Court of Appeal held that the regulations violated the family's rights under the Convention, as the Government had failed to provide objective and reasonable justification as to why it had failed to treat them differently from families whose situations were significantly different.

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[72] *A v Essex County Council (National Autistic Society intervening)* [2011] 1 AC 280, 161.

[73] See for example *Mathieson v. Secretary of State for Work and Pensions* [2015] UKSC 47; *Burnip v. Birmingham City Council* [2012] EWCA Civ 629; *Glor v. Switzerland* (2009) Application No. 13444/04 30th April; 2009; *Çam v. Turkey* Application No. 51500/08 February 24, 2016; and *Enver Şahin v Turkey* (2018) 30 January Application No. 23065/12.

[74] *Schwizgebel v Switzerland*, no. 25762/07 10 June 2010, *Khamtokhu and Aksenchik v Russia*, nos. 60367/08 and 961/11, 24 January 2017 and *Spišák v. Czech Republic* no. 13968/22 20 June 2024.

[75] *Thlimmenos v Greece* (2001) 31 EHRR 15; Application No. 34369/9731 6th April 2000.

[76] Ibid at para 44 and see *Burnip v. Birmingham City Council* [2012] EWCA Civ 629, para 14.

[77] [2012] EWCA Civ 629.

The UN Convention on the Rights of the Child (UNCRC)

3.45 The UK ratified the UNCRC in 1991, Article 3.1 of which provides:

> In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

3.46 The Supreme Court[78] considers that Article 3.1 not only generates an interpretative principle,[79] but that it also a creates a 'rule of procedure' – that:

> Whenever a decision is to be made that will affect a specific child, an identified group of children or children in general, the decision-making process must include an evaluation of the possible impact (positive or negative) of the decision on the child or children concerned … Furthermore, the justification of a decision must show that the right has been explicitly taken into account'.[80]

Article 23

3.47 Article 23 recognises that disabled children are entitled 'to special care' and have the general right to state assistance 'in a manner conducive to the child's achieving the fullest possible social integration and individual development'. The first paragraph of the Article refers to their right to a 'full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community' and paragraph 3 refers to the importance of disability related assistance being provided free of charge, whenever possible: assistance designed to ensure their effective access to (among other things) education, health care services, and recreation opportunities 'in a manner conducive to the child's achieving the fullest possible social integration and individual development'.

3.48 Guidance concerning the nature and extent of State obligations to disabled children under Article 23 was provided by the Committee on the Rights of the Child in 2006 as 'General Comment No. 9'. The General Comment requires (at para 13) that States:

> … develop and effectively implement a comprehensive policy by means of a plan of action which not only aims at the full enjoyment of the rights enshrined in the Convention without discrimination but which also ensures that a child with disability and her or his parents and/or others caring for the child do receive the special care and assistance they are entitled to under the Convention.

and at para 41, that:

> Children with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects. Such support to families includes … psychological support that is sensitive to the stress and difficulties imposed on families of children with disabilities; … material

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[78] *R (SG) v Secretary of State for Work and Pensions* [2015] UKSC 16, [2015] 1 WLR 1449, at paras 105-106.

[79] That where a legal provision concerning a child's best interests is open to more than one interpretation it should be interpreted so far as possible to confirm to the meaning ascribed to it by the UN Committee on the Rights of the Child, in its General Comment No 14 (2013) on Article 3.1.

[80] UN Committee on the Rights of the Child, in its General Comment No 14 (2013) on Article 3.1, para 6(c).

> support … that is deemed necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)

Article 4: the general obligation

3.49 The UK ratified the UNCRPD in 2009, Article 4 of which places the 'general obligation' on the UK Government to 'ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability' and to this end (among other things):

a. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;

b. To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;

c. To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

d. To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;

e. To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise.

Article 24: education

3.50 Article 24(2)(a) of the UNCRPD asserts that persons with disabilities must not be excluded from the general education system on the basis of disability. The UNCRPD Committee's General Comment 4 (2016) on Article 24 para 21 contains a requirement that educational institutions be accessible to everyone, without discrimination and that the environment of students with disabilities must be designed to foster inclusion and guarantee their equality throughout their education,[81] …. including hygiene and toilet facilities. This requirement is reinforced by the observation at para 52 that disabled student's 'ability to attend educational environments and learn effectively is seriously compromised by lack of access to health and to appropriate treatment and care' which includes, in the Committee's opinion 'students health and hygiene arrangements'.

Article 19: independent living

3.51 Article 19 of the UNCRPD recognises the equal right of all persons with disabilities to live in the community and (among other things) requires states to ensure that they have access to a range of services to support their right to independent living and to prevent isolation.

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[81] UNCRPD General Comment 2, Article 9, Accessibility, CRPD/C/GC/2.

3.52 The Committee on the Rights of Persons with Disabilities considers Article 19 to be 'one of the widest ranging and most intersectional articles of the Convention and has to be considered as integral for the implementation of the Convention across all articles'.[82] The Committee's finding in *Maria Simona Bellini v Italy* (2022)[83] illustrates this approach. The applicant cared for her disabled partner as well as for her disabled daughter. The Italian social system provided no support for family caregivers and only 'a very low disability allowance' for her disabled partner and her daughter.

3.53 Although the UNCRPD contains no explicit rights for family carers, the Committee accepted that in many instances 'the rights of persons with disabilities cannot be realised without the protection of family caregivers' and accordingly that Article 28(2)(c) of the UNCRPD 'recognises the right of family caregivers to State protection provided that this recognition is indivisibly linked to the protection of the rights of family members with disabilities'.

3.54 Article 28 concerns the right of persons with disabilities to an adequate standard of living for themselves and their families and Article 28(2)(c) requires the State to secure this right without discrimination on the basis of disability, in order to:

> ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care.

3.55 In its decision the Committee noted that (para 7.4):

> disability support services must be available, accessible, affordable, acceptable and adaptable to all persons with disabilities and be sensitive to different living conditions, such as individual or family income, and individual circumstances … [and reiterated that states had a duty to] provide adequate support services to family carers so that they can in turn support their relatives to live independently in the community.

3.56 That Committee considered that, on the facts, the Italian Government had violated the independent living rights (Article 19) of her disabled partner and her disabled daughter under Article 23. Article 23 requires states to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships. The Committee considered that this right included an obligation on the state to allocate specific financial, social and other resources to ensure that disabled people were able to live with their families without discrimination on the basis of disability. In addition, the Committee considered that the applicant's rights under Article 28(2)(c) had been violated[84] (as well as those of her partner and daughter).

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[82] General Comment No. 5 on Article 19 (2017) para 6.

[83] Committee on the Rights of Persons with Disabilities findings (dated 3 October 2022) concerning Communication No. 51/2018, a complaint by Maria Simona Bellini against Italy.

[84] The obligation in Article 28 to provide assistance to disabled persons and their families living on poverty is reinforced by the Committee's General Comment (No 5) concerning the interpretation and scope and of Article 19, that 'financial support is also crucial for family carers who often live in situations of extreme poverty, without the possibility of accessing the labour market' (para 68).

Domestic impact of the CRC and the UNCRPD

3.57 Although the relevant provisions of the CRC have been directly incorporated (to a limited degree) into Scottish[85] and Welsh[86] law, this has not as yet been the case in England. None of these three nations have, as yet, directly incorporated the UNCRPD into their domestic law. The lack of incorporation does not mean that the principles and the rights in these international treaties are of no relevance in domestic law proceedings. Where domestic courts encounter difficulties in understanding the meaning of a statutory provision (for example because it is unclear or ambiguous) then they are able to have regard to an international treaty that the UK Government has ratified. The basis for this 'interpretive tool' is the presumption that the UK would not make an international promise to respect the rights in the treaty and then legislate (or retain legislation) that contradicted this promise.

3.58 By way of example, in the *Gorry* proceedings (cited above)[87] the Government argued that the UNCRPD should not be used as an interpretative tool (to determine whether there had been unlawful discrimination). In the event recourse to the UNCRPD proved unnecessary as the court did not consider that meaning of the domestic provision was 'elusive or uncertain'.[88] However Maurice Kay LJ held that if it had been, then the court:

> ... would have resorted to the CRDP and it would have resolved the uncertainty in favour of the appellants. It seems to me that it has the potential to illuminate our approach to both discrimination and justification.

3.59 Not infrequently courts will also rely on domestic provisions that embody the principles in the unincorporated treaty. Accordingly, in 2009 the High Court cited with approval a statement that the promotion of independent living was 'a core – perhaps *the* core – principle underpinning the community care legislation'[89] and since that date the statutory guidance to the Care Act 2014[90] has asserted that:

> The wellbeing principle is intended to cover the key components of independent living, as expressed in the UN Convention on the Rights of People with Disabilities (in particular, Article 19 of the Convention). Supporting people to live as

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[85] The United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024 which applies when public authorities are exercising their functions under powers in an Act of the Scottish Parliament as well as ensuring that when Scottish legislation is enacted it is compatible with the UNCRC requirements.

[86] The Rights of Children and Young Persons (Wales) Measure 2011 requires that CRC the Convention is fully taken into account in policy development undertaken by Welsh Ministers - see generally S Hoffman and S O'Neill *The impact of Legal Integration of the UN Convention on the Rights of the Child in Wales* Equality and Human Rights Commission August 2018 at https://www.equalityhumanrights.com/sites/default/files/the_impact_of_legal_integration_of_the_un_convention_on_the_rights_of_the_child_in_wales_eng.pdf accessed 1 November 2024.

[87] *Gorry v Wiltshire County Council,* consolidated in the judgment *Burnip v Birmingham City Council* [2012] EWCA Civ 629.

[88] A similar approach was taken in *R (Davey) v Oxfordshire CC* [2017] EWHC 354 (Admin) paras 44–46 (upheld on appeal – see *R (Davey) v Oxfordshire CC* [2017] EWCA Civ 1308).

[89] *R (B) v Cornwall CC* [2009] EWHC 491 (Admin), (2009) per Hickinbottom J at para 6.

[90] Para 1.19.

independently as possible, for as long as possible, is a guiding principle of the Care Act.

3.60 Although the wellbeing principle in the 2014 Act only applies to disabled adults (and parents caring for disabled children[91]) a powerful argument could be made that children's social care legislation should be interpreted in the same way.

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[91] Section 17ZD (11) Children Act 1989.

4. Paediatric continence supplies and the policy context

Formal Government policy and practice guidance

4.01 As noted in the preceding chapter, although continence containment products are provided by the NHS in many regions within the three nations, very limited guidance has been issued by the three Governments concerning: (1) the process by which disabled children's entitlement to such products should be determined; and (2) the quality or quality of the products that should be provided. By formal guidance we mean guidance that is current and has been issued by a government (or by a statutory health body to which authority to issue such guidance has been delegated).

Formal English policy and practice guidance

The Department of Health; Good Practice in Continence Services (2000)[92]

4.02 The 2000 guidance (considered at the time to be a 'turning point' for continence services[93]) resulted from a Governmental review of continence services instituted in 1998. It is unclear as to whether this is still in force,[94] but given the expertise of the working group responsible for its development (listed in Annex 1 to the guidance) it must remain an influential Governmental statement of good practice. Annex 2 to the guidance ('Continence product supplies ') is germane in the context of this research and we set out below extracts from the Annex (with emphasis added) in those sections we consider to be of particular relevance.

- It is important to consider cost-effectiveness and quality of life rather than just product costs. A focus on costs alone is likely to be unsatisfactory for patients, is not conducive to treatment and will discourage companies from being creative and innovative in developing better products.
- There should be a range of pads available in all categories, including bed pads, a variety of sizes/absorbencies of body-worn pads with pants, and all-in-one products for special cases.
- Consideration should to be given to patient choice.
- There should be periodic re-assessment (at least yearly) of those receiving long-term supplies to check that needs have not changed, and that there is not a newer product available, which would be more suitable.
- In most cases it will not be appropriate to provide free pads before the age of four, but flexibility should be allowed for special cases such as children with multiple handicaps and decisions should be made in liaison with the designated paediatrician.

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[92] At http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4057529.pdf accessed 15 January 2025.

[93] W Colley 'Continence services in a changing NHS' Nursing Times 23 April, 2002 (98)17: 58.

[94] The guidance has been archived by – and is accessible at https://webarchive.nationalarchives.gov.uk/ukgwa/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005851 accessed 13 November 2024. None of the ICBs who responded to the FoI requests made reference to the 2000 guidance.

- Pads should be provided in quantities appropriate to the individual's continence needs. Arbitrary ceilings are inappropriate. Guidelines should be developed for the Primary Health Care Team to aid product choice, but these should not be seen as rules.
- 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.
- It is unacceptable to have waiting lists for pads as a means of rationing the service.

NHS England Excellence in Continence Care: Practical guidance for commissioners, and leaders in health and social care (2018)[95]

4.03 The 2018 guidance is a relatively brief document that provides little in the way of detail concerning the provision of continence containment products for disabled children. It however states in relation to 'children' generally (at page 11):

> It is essential that all children and young people with a bladder or bowel problem have a comprehensive bladder and bowel assessment by appropriately trained staff with the correct treatment and management programme put in place. Underlying bladder or bowel problems can otherwise be missed with potentially dangerous results.[96] It must be the exception, rather than the rule, that children and young people are provided with containment products.

4.04 It stresses the importance of continence support arrangements and required health commissioning bodies (then being Clinical Commissioning Groups) to have in place 'clear service level agreements with defined deliverables and standards of care' for the continence services that they commissioned (page 10).

4.05 The guidance cites with approval (at page 12) the 2016 version of the Bladder and Bowel UK 'Consensus document', stating that it:

> facilitates a consistent and equitable approach to the provision of continence products (such as nappies and pads) to children and young people aged 0-19 and offers impartial advice to ensure all children and young people who have not toilet trained or have urinary or faecal incontinence, undergo a comprehensive assessment and have access to an equitable service.

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[95] At https://www.england.nhs.uk/publication/excellence-in-continence-care/ accessed 10 November 2024.

[96] Citing Hicks JA, Carson C, Malone PS (2007) Is there an association between functional bladder outlet obstruction and Down's syndrome? Journal of Paediatric Urology 3(5):369-74 and Rogers J. (2012) Working with families to boost children's continence. Nursing Times. 2012 Dec. 11- 2013 Jan 14; 108(50):16, 18.

NHS England 2024/25 priorities and operational planning guidance (2024)[97]

4.06 In April 2024 the (then) Government published its ‘National objectives and planning guidance for 2024/25’. The guidance detail is of considerable relevance to ICBs in that it spells out the Government’s priorities and the basis upon which their performance will be measured. There is no reference in its 42 pages to continence services

Formal Scottish policy and practice guidance

4.07 There does not appear to be any formal Governmental guidance concerning the provision of paediatric continence containment products in Scotland. A guide ‘Promoting a Healthy Bladder and Bowel’[98] produced by NHS Western Isles[99] focusses on toilet training for children, but contains very little concerning the process by which families can access continence containment products for disabled children.

4.08 The Care Inspectorate for Scotland has published 2017 guidance: ‘Promotion of continence and management of bowel dysfunction Template policy for adult services’[100] but there appears to be no equivalent guidance of this kind for children’s services.

Formal Welsh policy and practice guidance

Welsh Government Circular WHC/2022/004 Guidance for the care of children and young people with continence problems[101]

4.09 WHC/2022/004 provides guidance for health boards in respect of the provision of continence containment products for children and young people. It does this by adopting the Bladder & Bowel UK guidance 2021 (considered below see para 4.20).

4.10 In adopting the BBUK 2021 guidance, the 2022 Circular suggests that this is an improvement on what went before, stating (at para 7):

> The current All Wales Children and Young People’s Continence Guidance and Care Pathway contains the statement *‘The maximum number of products issued will be four pads per 24 hours’.* The new guidance addresses this and contains the statement ‘The number of products issued per 24 hours **would normally not** exceed four, but provision should meet assessed need.’ This clinical need should be assessed by a professional trained in continence care. [emphasis in the original].

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[97] At https://www.england.nhs.uk/long-read/2024-25-priorities-and-operational-planning-guidance/ accessed 10 November 2024.

[98] At http://www.paediatriccontinence.scot.nhs.uk/wp-content/uploads/2024/05/Paedatric-Bowel-and-Bladder-Guidelines-2024.pdf accessed 12 November 2024.

[99] In collaboration with ‘Paediatric Continence Scotland’ (a NGO for health professionals) and Coloplast (a multinational company marketing – among much else – continence care products).

[100] At https://www.careinspectorate.com/images/documents/4184/HWT%20policy%20cover%20continence%20and%20management%20of%20bowel%20dysfunction%20MASTER.pdf accessed 15 November 2024.

[101] At https://www.gov.wales/paediatric-continence-containment-products-whc2022004 accessed 15 November 2024.

4.11 Unfortunately, this appears to be incorrect. The previous guidance (WHC/2017/044) stated that Welsh Government considered that to impose a maximum of four pads a day was 'inconsistent with public law principles and a breach of children's' dignity and it does not take into account the need for a full assessment' (para 8) and that for this reason, it revised the guidance, so that it stated '[t]he number of products issued per 24 hours would normally not exceed four, but provision should meet assessed need' (para 10). Contrary to this assertion, the revised guidance (i.e. the BBUK 2021 guidance) marked a backward step as it simply imposes a maximum and does not qualify this with the statement '*but provision should meet assessed need*'.

Non-governmental policy and practice guidance

4.12 In response to Freedom of Information requests made by the research team to health bodies in the three nations (para 5.06 below) reference was made to a number of non-governmental reports and practice guides. The three documents of most relevance are described below. Two of these documents were cited by health bodies in all three nations, however one (the first outlined below) was specific to Scotland.

Paediatric Continence Scotland 'Children's Continence Services in Scotland: A National Service Review' (2022)[102]

4.13 In 2022 'Paediatric Continence Scotland' (PCS) undertook a review of children's continence services in Scotland and published the above document. PCS is a network of health or allied professionals (from all HBs in Scotland) caring for children with bladder and bowel dysfunction and continence problems.

4.14 Although the aim of the publication was to draw attention to the parlous state of paediatric continence services in Scotland, its critical analysis provides a clear picture of what PCS considers to be the key characteristics of a fit-for-purpose service. As noted below (para 6.21) one HB made reference to the publication in its response to a FoI request made by the research team.[103]

4.15 In its conclusions, the Review noted (page 33) that:

> Children's continence services in Scotland are severely understaffed in the majority of HBs and are non-existent in some. The evidence shows that without adequate continence care, including prevention and early intervention, outcomes for children are poor. Long-term, chronic, stigmatising continence problems result when bladder and bowel dysfunction has not been recognised or adequately assessed and treated. Children with continence problems face being bullied, ostracised and excluded from school and family activities. School attendance and educational attainment may be poor due to chronic continence problems and their treatment; they are more likely to have suffered abuse and have a disability.

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[102] Morrison, C, *Children's Continence Services in Scotland: A National Service Review* (2022) Paediatric Continence Scotland at http://www.paediatriccontinence.scot.nhs.uk/wp-content/uploads/2022/10/Childrens-Continence-Services-in-Scotland.pdf accessed 25 November 2024.

[103] The FoI request asked for a copy of the guidance that the HB required practitioners to have regard to when authorising the provision of continence pads and containment products'.

> The lack of designated, continence services for children result in huge, avoidable costs to the NHS stemming from the unmet needs of children with continence problems, some of which persist throughout life, as well as the risk of reputational damage to the NHS.

Paediatric Continence Forum 2019 'Children's Continence Commissioning Guide A handbook for the commissioning and running of children's community continence services[104]

4.16 The Forum describes itself as a campaigning group of health professionals, patient representatives and commercial members that engages with the Government and policymakers nationally to raise awareness of childhood bladder and bowel problems and to improve NHS services in this area of child health.[105]

4.17 The 2019 guide provides information and tools for commissioners, clinicians and managers across the UK to set up and run integrated, nurse-led, community-based paediatric continence services.

4.18 It contains much valuable guidance on the incidence (and impact) of bladder and bowel difficulties and how a functional ('what 'good' looks like') continence care service should be configured and how it should respond to individual needs.

4.19 The guide provides no specific guidance concerning the provision of continence containment products – referring, however, to this issue in the following contexts:

- that it should be the exception, rather than the rule, that children with additional needs are provided with continence containment products; (para 1.2.1)
- as an argument in favour of a well-resourced, integrated community children's continence service in that it can considerably reduce overall costs by (among other things) reducing the 'need for disposable continence containment products'; (para 1.3 and 2.1)
- by advising that any continence service must have a sufficient budget to cover the costs of washable and disposable continence containment products; (para 1.5.4.5)
- by advising that all children with bladder and bowel dysfunction from birth – 19 years should be eligible for referral to the Children's Continence Commissioning Service. Children should not be excluded due to resource restrictions, or their age, additional need, or due to perceived lack of potential to be toilet trained; (para 1.6) and
- that one (or many) clinical outcome measures should be the 'reduction in the number of children who receive disposable products for continence containment against the number of children referred to the service with difficulties in toilet training; (para 2.3.3).

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[104] At https://www.bbuk.org.uk/wp-content/uploads/2019/12/PCF-Childrens-Continence-Commissioning-Guide-Dec-2019.pdf accessed 10 November 2024.

[105] At https://paediatriccontinenceforum.org/ accessed 10 November 2024.

Bladder & Bowel UK 2021 guidance

4.20 The NGO Bladder & Bowel UK (BBUK)[106] has published guidance that has been cited with approval by NHS England (see para 4.05 above), adopted as the official guidance in Wales by the Welsh Government (see para 4.09 above) and as our research demonstrates, is cited by many NHS bodies. The most recent iteration of the document is: 'Guidance for the provision of continence containment products to children and young people. A consensus document' (2021)[107] – referred to in this report as the BBUK guidance.

4.21 Although this research report expresses concern about aspects of the guidance (in so far as it applies to disabled children) it should be noted that it contains a great deal of expert and invaluable advice. It should also be stressed that the problems highlighted in this report result from a failure of health services in the three nations: (1) to publish formal fit-for-purpose guidance that specifically considers the needs of disabled children; (2) to impose and to enforce formal commissioning obligation on ICBs and HBs to ensure that fit-for-purpose services (including where necessary appropriate continence containment products) are available to support disabled children and their families; and (3) to provide adequate funding to ensure that such provision is available in practice.

4.22 Given the important role that the BBUK guidance has come to play, it is unfortunate that it (in the authors opinion) contains material that might be better expressed, and a number of what we refer to as 'embedded ambiguities' (which we consider in the analysis that follows).

4.23 The guidance commences with a 'disclaimer' that includes emphasis on the importance of professional expertise in this field and that its recommendations 'may not be appropriate in all circumstances and the decision to adopt specific recommendations should be made by the practitioner, taking into account the individual circumstances presented by each child and young person, as well as the available resources.'

Disability related discriminatory impact

4.24 The general thrust of the guidance is directed at children who are able to attain continence. It does not purport to be a specialist document concerning the support needs of disabled children who cannot attain continence (or for whom this may be long delayed) although it contains a number of references to the continence related challenges disabled children encounter. The guidance, however, emphasises that such children should be:

> assessed and treated in the same way as they are for children who do not have disabilities. This prevents discrimination, ensures that potential underlying

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[106] BBUK is a specialist team within the charity 'Disabled Living'. It provides a variety of services for health professionals, senior leaders in the NHS, Children's Services, NHS Trusts, Continence Service Leads and members of the public.

[107] BBUK 'Guidance for the provision of continence containment products to children and young people. A consensus document' (2021) at https://www.bbuk.org.uk/wp-content/uploads/2021/06/Guidance-for-the-provision-of-continence-containment-products-to-children-2021.pdf accessed 10 November 2024.

conditions, are not missed as well as ensuring cost-effective care with appropriate use of resources (Executive Summary p.5)

4.25 On one level, this advice is laudable, but other references to this approach in the guidance are of concern, suggesting that unlawful discrimination occurs when a disabled child is treated more favourably than one who is not disabled. For example on p.13 it states that 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 on p.17 this assertion is re-stated (without explanation), namely that '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 of the Equality Act 2010, as containment products are not provided for night time wetting to CYP who do not have additional needs. This approach is considered further at para 3.12 above and para 7.33 below.

Age

4.26 The BBUK guidance provides for what appears to be[108] a rigid age restriction – the age of five – below which continence containment products are not to be supplied. In practice (in those regions where there is a continence service) the evidence from those who have approached the LEaP programme for advice and from the BBUK guidance, indicates that the age restriction is sometimes greater as the child, once aged 5, then has to undergo a 'comprehensive continence assessment' (page 10).

4.27 The guidance provides no explanation as to why the age of five has been chosen, or an explanation why its guidance differs with the 2000 Department of Health guidance that specifies four as the relevant age (see para 4.02 above). Research suggests that the median age for the attainment of daytime bladder and bowel continence in all children is 2.4 years and that by the age of 3.1 years over 93% of all children are daytime bladder and bowel continent.[109]

4.28 However, for disabled children the data can be markedly different. A 2016 study of children with bilateral cerebral palsy,[110] for example, found that by the age of 3.1 years only 26% were bladder continent and only 24% were bowel continent. The research demonstrated that the rate of continence attainment from the age of 3 onwards was much more rapid in the 'all children category' – such that by the age of 5.5 years over 98% were fully continent, compared to

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[108] See for example, 'the provision of containment products to children and young people from the age of 5 years old' (Executive summary page 5); 'Only consider issuing containment products: once the CYP is over five years of age' (para 1.4); 'The provision of containment products to children and young people (CYP) would not be considered before the child's fifth birthday (para 2.1); 'CYP provided with disposable containment products will be over five years old (para 2.144) – but see also paras 4.26 – 4.29 below).

[109] A J Wright, O Fletcher, D Scrutton, G Baird 'Bladder and bowel continence in bilateral cerebral palsy: A population study' Journal of Pediatric Urology 12(6) Dec 2016, 383 e8, table 3 at e4, citing J Golding, M Pembrey, R Jones and the ALSPAC Study Team 'ALSPAC – the Avon longitudinal study of parents and children' I Study methodology. Paediatric Perinatal Epidemiology 2001;15(1) 74-87.

[110] A J Wright, O Fletcher, D Scrutton, G Baird 'Bladder and bowel continence in bilateral cerebral palsy: A population study' Journal of Pediatric Urology 12(6) Dec 2016, 383 e8.

children with bilateral cerebral palsy – for whom the figure was 51%. Indeed, by the age of 13.8 for children with bilateral cerebral palsy only 60% had attained full daytime bowel and bladder continence.

4.29 The actual figures will of course vary from one impairment condition to another but the evidence suggests (see para 2.04 above) that disabled children experience higher levels of incontinence and their ability to achieve bladder and bowel continence is more challenging than for children who are not disabled.

Maximum number

4.30 The BBUK guidance provides for what appears to be a rigid maximum on the number of continence containment products that can be provided to a disabled child. At page 15, for example, it states that the 'maximum number of disposable containment products that would be sufficient for most CYP is four per 24 hours'. This assertion is reiterated with slightly different phrasing at page 16 where it is stated that '[a]n appropriate number of containment products up to four per 24 hours to meet clinically assessed need will be supplied'. On the same page it is stated that 'parents and carers should be made aware of how to obtain more containment products'.

4.31 The guidance contains no explanation as to the reasoning or the underpinning rationale for the four-pad limit, or an explanation why its guidance differs with the 2000 Department of Health guidance that states, for example that '[p]ads should be provided in quantities appropriate to the individual's continence needs' and that '[a]rbitrary ceilings are inappropriate' (see para 4.02 above). Collectively the above guidance gives the strong impression that four pads per 24 is the maximum that can be provided by health services (and as this research demonstrates, in practice this appears to be the policy of most health bodies). Such a rigid restriction on provision would appear to be open to challenge on a number of grounds and this question is considered at paras 7.34 – 7.40) below.

Product restrictions

4.32 In section '2.122 Disposable containment products' (page 16) the BBUK guidance states that '[d]isposable pants are not supplied'. At page 4, it explains that pants of this kind are commonly referred to as 'pull ups' or 'pull up pants'.

4.33 Once more, the guidance provides no explanation as to why it differs from the 2000 Department of Health guidance that there should be 'a range of pads available in all categories, including ... a variety of sizes/absorbencies of body-worn pads with pants, and all-in-one products for special cases' and that '[g]uidelines should be developed to aid product choice, but these should not be seen as rules' (see para 4.02 above). The rationale for these restrictions is further analysed at paras 7.41 – 7.47) below.

Contradictory statements and embedded ambiguities

4.34 Despite the directive/mandatory tone of a number of the points made by the guidance, it contains several contradictory statements and ambiguities: statements that are difficult to reconcile with each other and, on occasions, appear out of context. For example, at page 9, (when outlining the purpose of the guidance) it states:

> '[t]o ensure that continence services do not have an arbitrarily assigned minimum age limit for CYP with disabilities or additional needs to access specialist assessment and treatment or support'.

If that is a purpose, it is one that is hard to discern when reading the overall document and one that in practice is not the experience of many families responding to the Cerebra survey.

4.35 Although the guidance gives the strong impression that local continence services should not become involved until a disabled child is five (for example at page 5. 'Key Recommendations' it states that 'Products would not be supplied before a child has reached their fifth birthday and then only after the child or young person has undergone a comprehensive bladder and bowel assessment') at page 12 it then states:

> Referral ... should be made as soon as any bowel/bladder problems are identified, or they are anticipated (for example children with diagnosed or suspected conditions, such as cerebral palsy, Down syndrome, or developmental disabilities, including autism). Where it is anticipated that CYP may have problems with continence or toilet training they should undergo assessment and be supported with a toilet skill development programme, appropriate to their individual needs. This should begin as soon as possible, ideally starting in the second year of life. This is in anticipation of a formal structured toilet training programme commencing as soon as the necessary skills are in place (see appendix 4). Those who have bladder or bowel problems would, therefore, be identified early and be offered investigations treatment according to need and best practice.

4.36 At page 14 the guidance then states:

> If the assessment indicates that the CYP has no potential for toilet training at this time due to an underlying anatomical, neurological or congential [sic] problem, such as neuropathic bladder and bowel, they have passed their fifth birthday and provision of containment products is appropriate, then an assessment tool for issuing of containment products ... must be completed.

4.37 This suggests therefore that assessments can commence much earlier for some disabled children but that regardless of their needs, no continence containment products can be provided until after their fifth birthday and after a further assessment has been undertaken. The advice as to a pre-fifth birthday assessment is of course welcome – although in practice this is not the experience of many families responding to the Cerebra survey. It is difficult however to understand why – when a disability related continence need has been identified, that a rigid restriction on support through the provision of continence containment products is nevertheless applied – something discussed further at para 7.32 below.

4.38 A further example of apparently contradictory advice in the guidance concerns the provision of pull up pants (considered at para 7.43 below). The guidance appears to state unequivocally that these are not supplied (para 2.122) – and in practice many parents responding to the Cerebra survey referred to this as causing significant problems.

4.39 At Appendix 7 to the guidance, it however states that:

> When assessing a CYP who is unable to acquire sufficient skills for successful toilet training for products, clinicians should consider all options available to ensure the most appropriate contaiment [sic] is provided for the individual.

4.40 The guidance then lists a series of products that ‘are all available and may be successfully used in CYP’. The list includes ‘One piece disposable products’ that ‘are available in a range of designs and sizes, including traditional shaped products (nappy-style), belted products and pant shaped products.’

4.41 These two statements appear to be contradictory – unless the meaning is that ‘pull ups’ are not supplied (ie by health services) but they ‘are available’ i.e. to purchase privately. This example of an ‘embedded ambiguity’ that is unhelpful and as we note below, appears to be the subject of differing local interpretations.

5. Research project methodology

5.01 The research programme involved four distinct dimensions: (1) analysis of anonymised survey data provided by Cerebra; (2) the making of Freedom of Information (FoI) requests and the subsequent analysis of the data provided; (3) searches of local Integrated Care Boards and Health Boards websites and the subsequent analysis of the data obtained; and (4) consideration of anonymised data (including interviews with disabled young adults who have used paediatric continence supplies throughout their childhood years) provided by the NGO The Parent and Carer Alliance C.I.C (P&CA).

The Cerebra Survey

5.02 An on-line survey (using an application called 'Survey Monkey') was posted by Cerebra on 27 June 2023 and closed on the 14 August 2023. The survey questions are detailed at Appendix 1 to this report.

5.03 A total of 105 replies were received by Cerebra. The data (anonymised) was then considered by the LEaP research team (including 48 *pro bono* student researchers) at Leeds University. The sample that was the subjected to detailed analysis was reduced by discounting 13 responses from respondents who had stated that they had not experienced difficulties getting continence products for their children as well as 1 response from the United States. As a result, the research team was left with a sample of 91 responses.

5.04 The survey comprised 14 questions. The analysis in this report focuses on the responses to Questions: Q6, Q7, Q8, Q9, Q10, Q12 and Q13.

FoI requests to local Integrated Care Boards and Health Boards

5.05 FoI requests were sent to a sample of 63 Integrated Care Boards and Health Boards, located in England, Scotland and Wales. These requests sought: (a) information concerning concerning the eligibility criteria that determined the type and the quantity of continence pads/ containment products that could be provided for disabled children within the Board's area; (b) copies of the guidance that the Board required practitioners to have regard to when authorising the provision of continence pads/containment products for disabled children; and (c) the work title (or post or qualifications or other designation) that identified the practitioners who could authorise the provision of continence pads/containment products for disabled children.

5.06 The FoI requests were sent in October/November 2023 (via the Boards portals and/or via emails to the addresses specified for such requests) and the responses analysed between December 2023 and January 2024. Appendix 2 of this document includes the text of the FoI request used for the English local Integrated Care Boards – the request (with the necessary changes) was also sent to every Health Board in Scotland and Wales.

Desk top analysis of local Integrated Care Boards and Health Boards' websites

5.07 To complement the information obtained as a result of the FoI requests, the websites of the 63 Integrated Care Boards and Health Boards, in England, Scotland and Wales were examined for evidence of their eligibility criteria and relevant guidance.

Interviews with disabled young adults and anonymised P&CA survey data.

5.08 It was deemed essential for the data analysis to include a consideration of the testimonies of young people who had experienced challenges in accessing paediatric continence supplies. To this end, the P&CA conducted and shared interviews with two of its members: disabled young adults who used paediatric continence supplies throughout their childhood years. Anonymised summaries of the two interviews are at para 6.35 below.

5.09 In addition, the P&CA undertook a short survey of its members by way of an on-line survey: anonymised extracts from the survey responses are at Appendix 4 below.

6. Research findings

Cerebra Continence Supplies Survey analysis

6.01 The on-line survey (para 5.02 above) sought the views of families concerning the accessibility, adequacy and suitability of paediatric continence support arrangements in their area. The survey questions are detailed at Appendix 1 to this report. The following sections describe the responses in qualitative/quantitative terms and in chapter 7 we critically analyse these findings in terms of their compliance with the demands of the law and public policy.

Quantitative restrictions on the provision of continence products

6.02 Respondents were asked (Q.6) if they had experienced a limit on the number of continence products that they had been allocated. Of the 73 responses to this question, 17 (23 per cent) explained that they had been unsuccessful in getting any support (either because they had been unable to access the service or that they had been refused support). In addition, eight of the responses were unclear – in the sense that they appeared to be commenting on a different issue. Of the remainder (48), 44 respondents (92 per cent) replied that they had experienced a limit and 4 respondents stated that they had not.

6.03 Of the 44 respondents who had experienced a limit on the number of products:

- The majority (16 – 36 per cent) of respondents stated that have been allocated a maximum of 4 daily products – and in at least in one of these cases, the respondent only achieved this allocation after 'fighting' with the service;
- 1 respondent had been allocated a maximum of 7 daily products – after 'fighting' with the service;
- 3 respondents had been allocated a maximum of 6 daily products – in one case only after challenging the original allocation;
- 3 respondents had been allocated a maximum of 5 daily products – in two cases only after challenging the original allocation;
- 4 respondents had been allocated a maximum of 3 daily products;
- 1 respondent has been allocated a maximum of 1 daily products;
- 9 respondents stated that they received products but that afterwards the allocation stopped – sometimes immediately, or after a couple of months;
- 7 respondents did not provide any additional information in the 'comments' box for this question, and therefore, it was not possible for the research team to know exactly how many products they have been allocated.

6.04 A comment box was provided for respondents who wished to add detail to their responses. Their comments included:

- *4 per day. Despite being double incontinent and on 3 different laxatives due to gut/constipation issues.*
- *Originally, they were allocated 4 a day but after a huge fight we now have 7.*
- *Initially 4 and now 6 in 24 hours. I was told to buy extra if I needed them.*
- *We are only allowed 3 pads per 24 hours.*

- *4 pull ups a day although we have been getting 5 a day. The worker who gave us 5 a day at her discretion has retired, and her replacement has said we will only get 4 that's the maximum. My grandson goes through about 10 a day.*
- *Was advised and prescribed stoma bags which do not work so advised to use double nappies/incontinence pads, never prescribed as under 4 (I believe) now at 5 nothing has ever been mentioned. All pads bought and paid for by me.*

The quality and fitness for purpose of continence products

6.05 Respondents were asked (Q.7) if they had experienced any issue(s) with the quality of the continence products. Of the 73 responses to this question, 15 (21 per cent) explained that they had been unsuccessful in getting any support (either because they had been unable to access the service or that they had been refused support). In addition, six of the responses were unclear – in the sense that they appeared to be commenting on a different issue. Of the remainder (52) 32 respondents (62 per cent) replied that they have experienced an issue with the quality and 20 respondents stated that they had not.

6.06 A comment box was provided for respondents who wished to add detail to their responses. Two issues dominated the comments that respondents left, namely: (1) concerns about the absorbency of continence pads and the consequential problem of leakage; and (2) problems due to the 'ill-fitting' of the pads and their size (particularly, this being a problem with 'nappies'). Other associated issues concerned the poor quality of the tab fixings such that they broke frequently or were insufficiently sticky. Several respondents expressed the importance of their child having 'pull-ups' (instead of nappies) and their frustration of being allocated poor quality/wrong size pull-ups or not being provided with pull-ups at all.

6.07 Specific comments included:

- *Many parents like myself found the pads crumbled so we needed extra (or different) but the service said they couldn't do anything as they had a 3-year contract.*
- *The inside of nappy will breakdown leaving my son covered in little white bits.*
- *The supply was changed from [XXX] products to a poorer quality product. This has resulted in almost constant leakage, as the wadding is insufficiently absorbent. The outer layer often splits during wearing, so the wadding then adheres to the inside of the user's trousers.*
- *Really big not suitable for 6 years child. Looks like adult pads.*
- *They wanted me to have nappies and not pull-ups and leaked at night.*
- *Not practical for school or overnight.*

6.08 Q.8 of the survey largely replicated Q.7 above, asking whether respondents had experienced any issue(s) with the type or make of the continence products. Specific responses in the comments box for this question included:

- *Pad filling crumbled and didn't hold the urine as a result, pads leaked in bed, in wheelchair, wetting clothes and bedclothes so we always had a lot* *of washing to do in addition to attending appointments for various services like epilepsy, back specialist, social worker, plus up to 30 other services a year.*

- *Big bulky nappies with tapes that would rip off making it useless.*
- *My son will never be able to manage his self-care needs while he has pads. School are saying his independence skills are being impacted due to not being able to manage his pads. He needs pull-ups to have any chance of gaining any independence around toileting.*
- *They only supply some brands and if your child doesn't like them tough luck.*
- *Not designed for babies/toddlers/young children.*
- *Cheap products.*

Additional challenges

6.09 Respondents were asked (Q9) if they had experienced other issue(s) in accessing continence products (i.e. apart from challenges relating to their quantity/quality). This question elicited 43 responses, some of which duplicated issues comments made in response to questions 6, 7 and 8 considered above. The distinct issue that emerged from the responses to question 9 concerned the inability to access any support:

- 5 (12 per cent) respondents mentioned the long waiting lists (a year or more) for access to support;
- 3 respondents referred to services with staff poorly trained or providing ‘general’/inaccessible leaflets which are not tailored to different impairment types;
- 3 respondents explained that they had not been made aware that such support was available;
- 2 respondents narrated their difficulties in reaching services over the phone;
- 9 respondents mentioned individual/various reasons explaining why they could not access any support (the GP tried to get support, but none available; scared of contacting the service; were told that products were only available for the night; were told nothing could be done; were told that nothing else was available; were told to use their DLA for purchasing products; were informed that the production of relevant products had been stopped; were told that there was no continence service for children in their area; could not see any consultant since pre-Covid).

6.10 Specific responses in the comments box for this question included:

- *I wasn't informed about what support I could receive for my child before they received an ECHP.*
- *No continence service for children commissioned in [XXX].*
- *Trying to even find a referral was hard work, then I was greeted by an extremely rude lady that said ‘you want free nappies?*
- *No child can be referred before age 4 and it’s a 12-month waiting list. After which you must carry out a 3-6 month toilet training regime before any products are supplied. Initial assessment suggested wildly inappropriate product…*

- *My son has toileting issues stemming from his mental health difficulties. I had to attend a toilet training workshop as part of the eligibility process. They had no advice to offer regarding our issues.*
- *One paediatrician suggested we cut a hole in the incontinence aids to let him poop through the hole. Another had us leaflets designed for children who have no learning disability but a phobia of using the toilet - designed for 3 and 4-year olds scared to train - all without understanding his specific needs.*

Adverse impacts resulting from inadequate continence care

6.11 Respondents who had encountered difficulties securing appropriate continence care/continence products for their child were asked (Q.10) to describe the impact that these difficulties had had on them and their child. Of the 73 responses to this question, 67 respondents (i.e. 92 per cent) responded to this question with details of these difficulties.

Community isolation

Families forced to limit outings with their children, and becoming isolated.

- *Having access to the wrong products, as well as not being able to access accessible changing facilities outside, contribute to this isolation.*
- *Constantly soiled clothing and bedding, sore skin, huge amounts of additional laundry. Got to the point where we hardly left the house because of incontinence and leakage etc.*
- *Very stressful worrying about not having enough pads, especially as disabled kids are ill more often and have diarrhoea more often but you still get same number of pads each time… It all adds to the stress especially for PMLD kids as you have to juggle so many services and appointments the last thing you want is worry about lack of pads, lack of adapted toilets, and not being able to go out anywhere as there is nowhere to change your growing child/teenager/young adult!*

Health issues

Children's health compromised, for example, through having nappy rashes and/or blisters.

- *His skin suffered rashes.*
- *Pads were poorly fitting and caused severe blisters on my daughter's skin.*

Pain/discomfort

Children in pain/discomfort.

- *My son's school would complain about the nappies asking me to provide different nappies as my son was uncomfortable and often sore.*
- *My son was often uncomfortable, we were both impacted, I would be worried and frustrated trying to keep my son comfortable and treating nappy rash and my son was in pain.*

Loss of confidence/self-esteem/identity/socialisation

Children became dysregulated and lost confidence as well as self-esteem. Their identity was negatively impacted, as they felt infantilised.

- *My son also saw these as baby-ish whereas a pull up were more like 'pants'.*
- *This meant the pulls up we have are either too tight on him or he has wet bed every night, leading to him being dysregulated and losing his confidence.*
- *Having the wrong type (and amount) of allocated products causes leakages, soiled, wet and smelly continence products. The impact on the children and their families is massive.*

Impact on other care and support services

Some parents explained how their children's carers refused to use the allocated products (as they deemed then unsuitable).

- *Our carers refuse to use them even in emergencies as they are so unsuitable.*
- *It has added to the other barriers to going out and about and maintaining her sit to stand ability. Carers supporting her found sit to stand too difficult using nappy product so her days out are cut short so she comes home to use the change bed or hoist or she is limited to going where there are changing places facilities with her carers.*

Impact on schooling

For those children in school settings, families reported that because of the faulty access to the right continence products, their children's engagement with/at the school suffered – for example by creating difficulties in making friends and experiencing bullying.

- *My child struggled throughout year[s] 4-6 in primary school. As a result of [not having the right continence products] they struggled to make friends and their education was challenging for them.*
- *When she has accidents, she is bullied as she smells as only has pants.*

Financial impact

A major finding concerns the consequential financial impact on families: families having to pay for the cost of continence products; having to pay for several washing loads of clothes and bed clothes; having to replace clothes, bedclothes and protective mattresses; having to have pay for carpet and other upholstery cleaning due to leaks and so on.

- *We have been made to spend so much money just to let our son go to the toilet hygienically and with dignity. It has had a huge impact on our lives. I had to give up work initially to care for my son and go through all the issues getting diagnosis etc and then to have to pay this on top of an already difficult situation is scandalous. We are paying huge bills for* *washing and drying too as incontinence means soiled clothes and bedding - especially as he strips too due to sensory issues and autism.*

- *My child is still in nappies, we are financially struggling very badly. After a long time when support provided that wasn't suitable at all and they said we can't do anything.*

Systems Generated Trauma

Parents expressed their frustration and despair as the result of dealing with inaccessible children's continence services, and the faulty provision of appropriate products for their children. Many fell into depression and stress. Several referred to the number of phone calls they had had to make and the arguments they had had with the service. In some cases, they reported that they could not access the service at all (for example, because of their child's age or the impossibility of making meaningful contact with the service.

- *Stress… frustration, zero face to face until I received the products… If my daughter can't even answer to her name how on earth is she to potty train. So awful.*
- *The stress it creates really starts to affect your mental health and I still vividly remember bursting into tears with frustration the last time they tried to cut his supply.*

Often (and inevitably) falling into many of these categories

- *The pads supplied are ill fitting and not suitable for my son. He regularly uses one hand to support his crotch as the pad hangs down and he can feel it, which he struggles to tolerate due to his sensory issues. He then struggles to engage in learning at school because he only has one hand free, and is preoccupied with his pad. We are having to buy pull-ups when we can afford them, to try and support him while in school. For the Local Authority to insist on supplying a product that is not fit for purpose, and one that denies a child the right to a level of independence is inexcusable!*
- *Financially massive impact as 8 training pants is going to cost over £100 - not including delivery. Sizing of nappies meant that although she's needed a bigger size of the [named nappy brand] taped, we've intentionally kept her in nappies that are too small as the next size up available to us is massive - not good for a child in a mainstream school for her dignity.*

The provision of reasons for the refusal/limitation of continence supplies

6.12 Respondents were asked (Q.12) if they had been given an explanation for the refusal/limitation of continence supplies. Of the 73 responses to this question, 32 (44 per cent) stated that no explanation had been provided, 39 (53 per cent) provided details of the reasons they had received; one indicated that the question was inapplicable as they had not sought continence care products; and 2 failed to provide the explanation that they had been given.

6.13 Of the 39 respondents who detailed the reasons they had been given:

- the most commonly reported 'reason' (given by 16 respondents) was that the service did not provide what was being sought: that the service was run on the basis of rigid rules that severely restricted access to continence products – both in terms of quality and quantity. Not infrequently this state of affairs was justified in terms of budget constraints (5 respondents);
- 4 respondents stated that they were told the argument that the service is set up for contributing (and not fully meeting) the needs at stake;
- 3 respondents were told that their child was not fully incontinent;
- 2 respondents stated that the service referred to the NICE guidance;
- 2 respondents were told that they had to use their DLA;
- Additional individual respondents mentioned various reasons: the service no longer offered pull-ups; the assumption that nappies should last up to 12 hours (therefore 4 nappies being a reasonable amount); night time products being unavailable; the age of the child being outside the age range for offering products; certain brands unable to obtain plastic to make the continence products; they had stopped providing products; they had stopped offering pull-ups.
    - *They no longer offer pull up products is what they said.*
    - *They say it is up to parents to buy more and they can only supply a certain amount. They also try to prescribe medication to stop children having a wee or a poo at night so that they don't have to provide a pad. The medication comes out of the GPs budget not theirs.*
    - *Apparently as she only needs them to open her bowels, they will not provide nappies.*
    - *Budget funds and belief NHS shouldn't fund everything.*
    - *I was told that they offer a 'top up service' and that they will supply just 3 pads per day and that I should pay for any additional pads required. I also required continence sheets for his bed but was refused those as I was told they would only supply me with 1 product.*
    - *That's what my DLA is for.*
    - *As nappys [nappies] should last up to 12 hours, 4 per day is a reasonable amount.*
    - *Age in the beginning.*
    - *[Brand] unable to obtain plastic to make the products.*

Accountability and redress

6.14 Respondents were asked (Q.13) if they had complained about the refusal/limitation of their child's continence supplies, and if so, to describe the outcome their complaint. Of the 73 responses to this question, 22 respondents (30 per cent) stated that they had complained (or tried to complain) and one stated that they had threatened to complain.

6.15 Nine (40 per cent) of the 22 respondents who had complained/tried and/or threaten to complain to their local health service achieved a positive outcome. 7 of the respondents who had complained (with a negative outcome) explained that they received 'arbitrary' replies as to why they were not successful – for example, that this is how things are and there is nothing the service could do. 2 respondents stated that they tried to complain but were too exhausted to follow it up. 3 respondents explained that they had found the complaints' system inaccessible – for example, it was not possible to contact anyone working for the service. 1 respondent did not provide additional detail about the process/outcome of their complaint.

- *This is how I managed to eventually get the increase.*
- *Not formally yet but plan to do.*
- *I complained on the phone - not a formal letter or anything - they just said that this was the situation and there is nothing they can do.*
- *Tried to escalate via district nurses, they were gatekeeper for access to continence team who would not speak to me. They said they could provide more of a lesser absorbent pad which is ridiculous as I'd have more washing from leaks! In the end I gave up as process was ridiculous. They could not signpost me to a complaint process. I tried phoning and emailing the Healthwatch but never had a reply.*
- *I challenged it and got it increased to 6 per day. It took a long time and was a battle.*
- *They said 4 a day is the rule.*
- *I'm an exhausted mother of a SEN child, I don't even know who to complain to…the whole system is shot to bits and is so utterly draining.*
- *Can't get hold of anyone they never take calls or respond to emails.*

Freedom of Information (FoI) requests and desk top analysis concerning FII training and guidance

FoI requests

6.16 As noted above (para 5.06) FoI requests were sent to 42 English ICBs, to 14 Scottish HBs and to all seven Welsh HBs, seeking information as to: (a) the eligibility criteria that applied in their areas for the provision of containment products for disabled children/young people; (b) the relevant guidance that the Boards has adopted in relation to the provision; and (c) the work title (or post or qualifications or other designation) that identified the practitioners who are authorised to provide these products.

Responses from English ICBs

6.17 Of the 42 ICBs who received the FoI request, 36 (86 per cent) failed to provide any information:

- Only 2 ICBs provided a complete substantive response to the FoI request;
- 1 ICB provided substantial information for two regions within its area, but stated that the research team should write to a named NHS Trust for the information concerning the remaining region;
- 3 ICBs provided information in relation to requests (a) and (b) but referred the research team to provider organisations/Trusts/a Community Interest Company (CIC) in relation to request (c);
- 2 ICBs did not reply to the FoI request;
- 1 ICB responded by stating that it did not hold the relevant information;

- 33 ICBs failed to provide any information and referred the research team to other bodies, including NHS Trusts, CICs, Councils and 'service providers'.

6.18 Of the 6 ICBs that responded to FoI requests (a)[111] and (b):[112]

- 1 ICB stated that part of its area of services followed the 2021 BBUK guidance (guidance discussed at para 4.20 above). This ICB also attached a document that contained no material relevant to the specific FoI request;
- 1 ICB stated that 'the community provider will assess for and prescribe clinically appropriate continence products where indicated wherever patients reside in [XXX]'. This ICB also attached a document that contained no material relevant to the specific FoI request;
- 1 ICB attached the document 'Policy for the clinical assessment of Continence for Children with GP in [XXX] ICB'. According to this document, 'children over the age of 5 years old with physical and learning disabilities, or developmental delay, who have not achieved continence' were eligible to receive continence containment products (p. 18). This was subject to the stipulation that the children 'have a trial of toilet training for at least six months' (p. 18). The policy also stated that only 4 products could be provided per 24 hours and that pull-ups could not be provided as 'there is no clinical evidence that they promote toilet training and are less absorbent that other disposal products' (p. 18).
- 1 ICB stated:

  > Children and Young People (CYP) with disabilities are supported to attain continence and are treated in the same way as a non-disabled child. Assumptions are not made about the potential for a child to become continent and face to face assessments are undertaken to determine if support can be provided to help a child achieve this before requiring containment products/continence pads. Should the assessment indicate that Children and Young People (CYP) has no potential for toilet training at this time due to an underlying anatomical, neurological or congenital problem or if appropriate skills have not been learnt following a programme of support, an assessment will be undertaken for containment products /continence pads. In general, children are supplied with no more than 4 pads per 24 hours although this may vary depending on clinical need.

  This ICB attached several documents[113] - none of which contained the criteria relevant to the FoI request.
- 1 ICB replied stating that it followed the 2019 BBUK guidance.
- 1 ICB attached a document entitled 'Continence Framework for [XXX]'. This document states that:

  > Children/young people over the age of 5 years (or under 5 in exceptional circumstances i.e., chronic constipation) who have a diagnosed medical condition, which is the cause of their incontinence, may be eligible to receive continence support if indicated if indicated, after a comprehensive

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[111] Namely the eligibility criteria they used to determine the type and quantity of the continence pads and containment products provided.

[112] Namely for a copy of the guidance that they required practitioners to have regard to when authorising the provision of continence pads and containment products.

[113] Paediatric Assessment Tool for Toilet Training Readiness and Issuing of Products; Specialist Paediatric Continence Reassessment for Products; Specialist Paediatric Enuretic Assessment; Specialist Paediatric Bowel Assessment.

> assessment and care plan is undertaken by a relevant health care professional. (p. 5)

6.19 3 ICBs responded to the final FoI request (c).[114] Their responses stated: (1) 'registered Nurse and Specialist Community Public Health Nurse'; (2) 'qualified registered children's nurses or registered general nurses that have undertaken a variety of credited university modules for children's continence and regular training updates' (also including a 'Bladder and Bowel support worker'); and (3) 'Bladder and Bowel Nurse specialist'.

FoI requests to Scottish Boards

6.20 All 14 Scottish Health Boards (HBs) provided substantive responses to all questions in the FoI request.

6.21 In relation to the first FoI requests (a)[115] and (b)[116]:

- 1 HB attached the document 'Continence Assessments and Management Guidelines 2014', which (in relation to the eligibility criteria for accessing containment products) states that children up to 16 years with urinary and/or bowel problems are eligible; that products are not supplied until the child is four years of age; that children with special complex needs may be eligible until they complete their education which may be up to the age of 19 years (p. 6).
- 1 HB stated:

> Continence Products are issued after evidence that parents have tried to put a toileting routine in place to try and get the child to be continent. Products are offered to children over the age of five years of age. We offer support through our Health Care Support workers to support the toilet training if required.
>
> For children who have complex disability or where it is medically determined that there is no chance of the child becoming continent an assessment will be undertaken and products provided at the child's fifth birthday. Each child is required to have an assessment and then after discussion with the family a product sample is sent to the family to trial before setting up the order. Ontex provide all our products and sample list is attached. There is a max of five products a day issued after assessment, and this is reviewed annually.
> Most of our referrals for children requiring products come through the health visiting service.
> The continence products service is part of our Healthy Bowel and Bladder service overseen by RSCN qualified nurses and trained health care support workers who can offer further support.
>
> For information I attach the guidance NHS [XXX] use by Healthy Bowel and Bladder UK for provision of products and the Ontex formulary is attached for availability of products.

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[114] Namely for details of the practitioners authorised to provide continence pads and containment products.

[115] Namely the eligibility criteria they used to determine the type and quantity of the continence pads and containment products provided.

[116] Namely for a copy of the guidance that they required practitioners to have regard to when authorising the provision of continence pads and containment products.

  This HB attached a document ‘Paediatric Assessment Tool for Toilet Training Readiness and Issuing of Products’ which contained no criteria relevant to the FoI request.

  - 1 HB referred to the 2021 BBUK guidance. In line with this, the HB stated:

    > NHS [XXX] provide containment products to all children over the age of 5 who meet the clinical need for a prescription. There is a requirement of a completed assessment form and voiding chart prior to a prescription given. As a standard a provision of no more than 4 containment pads will be issued. However, if the clinical evidence given matches a need for more that will be considered.

    This HB also attached the documents ‘Paediatric Assessment Tool for Issuing of Products’ and ‘Referral form to request containment products for children and Young people aged between 5-19 years’, neither of which contained criteria relevant to the FoI request.

  - 1 HB replied: ‘Following assessment, the NHS [XXX] Children and Young Adults Continence Product Formulary Community Core Form would be used to ascertain the correct product for the child/young person. In addition, this HB attached the 2021 BBUK policy.
  - 1 HB referred to the 2021 BBUK document.
  - 1 HB attached the ‘NHS [XXX] Continence Product Formulary Community Children’s which contained no criteria relevant to the FoI request. This HB also attached the 2021 BBUK document.
  - 1 HB attached the guidance ‘NHS [XXX] Guidelines for Prescribing Continence Containment Products to Children in the Community’. This HB stated that these guidelines ‘are currently under review to reflect changes in national guidance’, adding that:

    > According to this document, an ‘assessment will be carried out for all children with an identified continence problem’ (p. 3). It is stated on this policy that children under the age of 4 will not be provided with products (p. 4 – also see this document for additional exclusions). Regarding pull-ups, this document clarifies that these ‘should not be supplied if toilet training is trying to be achieved’ (p. 6).

- 1 HB replied that their continence services do not distinguish between children with disability and those without. It attached the document ‘NHS [XXX] Children & Young Adults Continence Product Formulary’ – which contained no criteria relevant to the FoI request. It also attached the Paediatric Continence Scotland ‘National Service Review’ (see para 4.13 above) and explained that it was currently evaluating this document.
- 1 HB replied that it did ‘not have specific criteria for the provision of continence aids for disabled children’ and attached the 2021 BBUK policy.
- 1 HB replied:

  > The type and quantity of a product is ideally determined by the outcome of the continence assessment. Products should not be the first choice if other recommendations could be considered such as consistency in toileting etc. Children under five years of age are not routinely provided with products as per protocol (we currently use the protocol provided by NHS [XXX]).
  >
  > There are benefits available for disabled children to facilitate the purchase of products under five years of age which are not means tested.

This HB attached the 2021 BBUK guidance. It also attached the 'NHS [XXX] Continence Product Formulary. Community Children's' and the 'NHS [XXX] Continence Product Formulary. Acute Children's' neither of which contained criteria relevant to the FoI request.

- 1 HB attached the document 'NHS [XXX] Guideline for the Assessment of Toilet Training Readiness and the Issuing of Products'. This document states:

  > There is no statutory requirement to provide continence products to children under the age of five, although most areas, including NHS [XXX], provide products from four years old, based on an assessment of clinical need. Those children with a physical or learning disability that impacts directly on their ability to achieve continence, and whose individual continence needs differ from children of a similar age within the general population, will be considered for provision of products. This will be reviewed at least six monthly. (p. 5)
  >
  > All children should have a documented assessment and trial of toilet training, if appropriate, prior to the issue of any product. It could be considered as active discrimination, in relation to the child's disability, if these children are not offered the same continence promotion service as any other child, who presents with a wetting or soiling problem. (p. 5)

- 1 HB referred to the 2021 BBUK guidance. It also attached the document 'Paediatric Assessment Tool for Issuing of Containment Products' – which contained no criteria relevant to the FoI request.
- 1 HB stated:

  > Children and young people should receive support to achieve their potential for the attainment of continence, regardless of their age, culture or ability. Children with disabilities are also supported to attain their potential in this area of development, and any underlying bladder and/or bowel issues are assessed and treated in the same way as they are for children who do not have disabilities. This prevents discrimination, ensures that potential underlying conditions, are not missed as well as ensuring cost-effective care with appropriate use of resources.
  >
  > The 'custom and practice' of automatically providing products to children with an acknowledged disability once they have reached a particular age e.g. their fifth birthday, is not appropriate and could be considered discriminatory.

  This HB also attached a copy of the 2021 BBUK guidance.

- 1 HB attached the policy 'Bladder and Bowel Nursing Team NHS [XXX]'. Provision of Incontinence Products to Children and Young People in the Community Guidelines'. Version 3'. This document states:

  > All children and young people who are delayed or struggling with toilet training must undergo a comprehensive bladder and bowel assessment by a competent practitioner with the necessary knowledge and expertise. They should be supported with a toilet training programme appropriate to their individual needs for at least six months prior to providing containment products (unless it is clear that they will be unable to toilet train, for example neuropathic bladder and bowel). (p. 5)
  >
  > The children or young person is required to be registered with an NHS [XXX] GP.
  >
  > - Children, five years and older, with a physical, psychological or learning disability that impacts directly on their ability to achieve continence or

where there is an underlying medical condition causing incontinence (urinary and/or faecal).

- All children and young people with an identified bladder and/or bowel dysfunction must be offered a comprehensive clinical assessment with first line treatment undertaken and reviewed. The Bladder and Bowel Nursing Team require evidence of completed assessments prior to approval for products.
- Individuals will self-fund products until a clinical assessment and treatment plan implemented has been completed.
- Staff must be aware of the potential for misuse of products supplied by the NHS and ensure that ongoing re-assessments reflect the child or young person’s actual clinical and continence needs. (p. 6)

6.22 In relation to the final FoI request (c):[117]

- 12 HBs (86 per cent) stated that nurses (‘registered nurses’ and ‘continence specialist nurses’) can authorise the provision of continence pads and containment products;
- 1 HB replied that ‘there is not an identified service provision, or designated practitioners in [named HB] with responsibility for assessing and authorizing continence products for children and young people who are school aged’;
- 1 HB replied that their Continence Adviser can authorise the provision of such products.

FoI requests to Welsh Boards

6.23 All 7 Welsh HBs provided a substantive response to all questions in the FoI request.

6.24 In response to the FoI requests (a)[118] and (b):[119]

- 1 HB attached the document ‘[XXX] Policy for the provision of continence containment products to children and young people’. This document establishes that ‘normally’ continent products will be provided to children and young people aged 5-19, after a comprehensive assessment and per 24 hours the number of products issues would normally not exceed 4 (pp. 5 and 6). This HB also replied that they follow the 2021 BBUK policy.
- 1 HB referred to the Welsh Health Circular (WHC) 2022 policy for containment products and the 2021 BBUK policy.
- 1 HB attached the document ‘Bladder and Bowel Service. Criteria for the Issuance of Continence Pad Products’. In relation to children, this document refers to the ‘individual HB assessment documentation and Welsh Government Guidance, RCN and Bladder and Bowel UK Guidance for the provision of continence containment products to children and young people A consensus document 2021’ (p. 1).

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[117] Namely for details of the practitioners authorised to provide continence pads and containment products.

[118] Namely the eligibility criteria they used to determine the type and quantity of the continence pads and containment products provided.

[119] Namely for a copy of the guidance that they required practitioners to have regard to when authorising the provision of continence pads and containment products.

- 1 HB attached the document ‘Promotion of Bowel and Bladder Health in Children and The Provision of Containment Products’. This document states that it has to be read in conjunction with the 2021 BBUK guidance. In addition, it establishes that:

  > When it is determined that a child may need the provision of containment products (Appendix 6) the HV will discuss with the CNSCAN and complete a ‘Paediatric Assessment Tool for Issuing of Containment Products’ (Appendix 4). Containment products are only supplied for children after the age of 5 years. However, there are rare exceptions, e.g., palliative care. (p. 10)

- 1 HB attached the document ‘Continence Care Policy’. This document states:

  > All children and young people must receive support to achieve their maximum continence potential, regardless of age, culture, or physical and psychological ability. Containment products must only be supplied following a full assessment by an appropriately trained health care professional e.g. health visitor, school nurse and only when toilet training is not deemed as achievable. (p. 23)
  >
  > This document aims to facilitate a consistent and equitable approach, to continence care for all children and young people aged 0–19 and to the provision of containment products to children and young people from the age of 5 years old, who are not able to become continent within six months of engagement with appropriate support, interventions, and/or toilet training programmes, by bringing together a consensus of agreement, combining the available evidence from the literature and clinical expertise. (p. 23) However, there will be times when individually assessed circumstances warrant an approach outside the guidance. (p. 23)
  >
  > The number of products issued per 24 hours would normally not exceed 4, but in exceptional circumstances, provision will meet assessed individual need. (p. 24)

  This policy document cites the 2021 BBUK guidance.

- 1 HB referred to the 2021 BBUK guidance.
- 1 HB referred to the Welsh Health Circular (WHC) 2022 policy for containment products and the 2021 BBUK policy.

6.25 In response to the final FoI request (c)[120] the information provided suggested variations between HBs – for example in one HB it was specified as a registered nurse; in another ‘specialist health visitors’ and another specified Bladder and Bowel Health Service qualified staff.

Desk top analysis

6.26 Searches of the websites of 63 Health Bodies (42 English ICBs, 14 Scottish HBs and 7 Welsh HBs) were undertaken to augment the data obtained via the FoI requests.

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[120] Namely for details of the practitioners authorised to provide continence pads and containment products.

Web searches for English Boards

6.27 Web searches of 42 ICBs were undertaken. In 39 (93 per cent), the research team was unable to find any information about how continence products for disabled children could be accessed.

6.28 Of the remaining three ICBs, the position was as follows:

One ICB provided links to various continence policies for children including the BBUK (2019) guidance and contained a 'Referral Form – Continence Service for Children and Young People' which included the following criteria that had to be satisfied for its service to be accessed.

- Children and Young People aged 4yrs – 18yrs, who are experiencing daytime wetting, night time wetting and/or constipation/ soiling/ withholding.
- … evidence of Tier 1 input (minimum of 3 months) ie food charts/toileting charts/advice given.
- Young people, who attend a [XXX] Special School, will be accepted up to 19yrs, when they will be transitioned to The Adult Bladder and Bowel Services if deemed appropriate.
- Referrals accepted from Health Professionals/ Education Professionals.
- Children and Young People who require/have continence products will undergo an assessment to determine need, and this will be assessed annually.
- Child or Young Person who has been treated at a local CED/A&E for impaction, on 2 separate occasions, within a 3 month period.

It has not been possible to cross check this website information with the ICB's FoI response as in its response it had stated that it did not hold the information (merely referring the research team to two NHS Trusts) – see para 6.19 above).

Of the remaining two ICBs the only relevant information on their websites were their respective responses to the FoI requests that had been sent by the research team.

Web searches for Scottish Health Boards

6.29 Web searches of all 14 HBs were undertaken. In 12 of these (85 per cent), the research team was unable to find any information about how continence products for disabled children could be accessed.

6.30 Of the remaining two HBs, the position was as follows:

1. The website of one HB contained eligibility criteria for the provision of containment products for disabled children: criteria that matched the criteria it had provided on its FoI response to the research team.
2. One HB published the 2021 BBUK policy on its webpages, however this was a HB that had responded to the FoI request by stating that it had developed its own (local) continence policy.

Web searches for Welsh Health Boards

6.31 Web searches of all seven HBs were undertaken and in every case, it was possible to find some relevant information i.e. details of eligibility criteria and/or relevant guidance concerning the assessment process and/or authorised prescribers.

6.32 Five HBs' websites provided information as to their applicable eligibility criteria – being information that they had provided in response to a FoI request (a request sent by a third party – i.e. independent of this research programme). For the remaining two HBs the website information was materially different to that they had provided response to the research team's FoI request.

6.33 Four HBs posted information on the webpages about the guidance they follow when authorising the provision of continence containment products for disabled children (and three HBs did not).

Three of the HBs posted information that was materially different to that they had provided to the research team in response to its FoI request.

The relevant website information for the remaining was an older version of the policy that it had referred to in its FoI response.

6.34 Only two HBs provided details on their websites concerning or authorised prescribers.

Voices of disabled young adults who have used paediatric continence supplies during their childhood/teen years

6.35 The following are two accounts/findings from interviews provided by 2 disabled young adults, and whose names have been anonymised.

Mary, 22 years

I was born with a condition that meant that I had bladder and bowel diversions. After 17 years, I was diagnosed with overactive bladder.

I experienced a lack of understanding, and poor communication with services. They didn't seem to believe me.

It feels like it is a never-ending advocating battle… no matter how old you are, you have to advocate for what is right.

I feel that there is a huge stigma around people with special educational needs having these continence issues.

The lack of understanding from the continence services made me feel invalidated. They were almost continuously making me feel stupid and… that it was me that was the problem rather than their inaccurate training.

I don't really feel like I had a childhood in that sense… I think it's like it damaged me to this day. I have lost all trust and faith in my continence team.

I've heard of young people that have been injured or experienced… severe consequences for their bladder and bowel assessments that haven't been done promptly.

Those new to the system need to have a holistic approach… They [the services] need to not parent blame and say about potty training…. Because I know a lot of neurodivergent children who maybe reach much later the milestones of potty training.

Peter, 27 years

I had issues with my bladder from primary to secondary school. I also have epilepsy.

The only advice given by the Dr. to me and my Mum was that I should stop drinking at 8'clock at night. But it didn't work.

I think that we were almost left to deal with it ourselves.

I felt annoyed that ono one was helping more or checked what was happening. This was very upsetting for me and my Mum.

I also felt quite thirsty during the evenings.

At school, I was tired after waking up many times during the night. Most of the nights I woke my Mum up like maybe two or three times, because I did not want to go back to sleep into a smelly and wet bed… and I need to get cleaned.

I feel that having more help, and explanations instead of just advice, would have helped.

7. Discussion and analysis

7.01 The many and distressing accounts provided by families of their difficulties in accessing appropriate continence products provided the impetus for this research report. Summaries of these responses are contained at Appendix 3 and Appendix 4 and an appreciation of the profound harms that they reveal, provides an essential 'point of departure' for the analysis that follows.

The impact of inadequate provision

7.02 What the literature tells us (see paras 2.03 – 2.06 above) is that the failure to provide adequate care for bladder and bowel conditions can cause incalculable harm to individuals. Although the literature is dominated by accounts of the harm experienced by adults, over 90 per cent of the respondents to the Cerebra survey described adverse impacts that they and their children experienced as a result of these difficulties: many of whom used the language of human rights to describe the indignities and harm they and their children experienced.

7.03 At chapter 3 (paras 3.20 - 3.56 above) we provide an overview of the human rights provisions and case law that are of particular relevance to the subject matter of this research report. There can be little doubt, but that many of the distressing indignities described by respondents to the Cerebra and the P&CA surveys are of such severity to engage these fundamental human rights: accounts of disabled children experiencing conditions that are objectively degrading; of severe interferences with their private and family lives; of unlawful discrimination; and inexcusable interruptions in their education.

7.04 In addition to the case law we describe, there is a not inconsiderable literature concerning the extent to which a state's obligation to provide continence containment products can engage its fundamental human rights obligations. In almost every case, however, the literature describes the experiences of older people in some form of institutional accommodation.[121]

7.05 By way of example, a 2022 report by the Joint Committee on Human Rights[122] concluded that the inadequate provision of incontinence products for adults in care settings 'could amount to a breach of the state's obligations to protect individuals against torture and inhuman or degrading treatment (Article 3 European Convention on Human Rights (ECHR)), as well as to a violation of the central principle of human dignity, which underpins human rights protections.' The Committee noted, however, that although its report did not cover matters of specific relevance to children's care 'considerations made in

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[121] See for example, D Gove, A Scerri, J Georges, P van Houten, N Huige, D Hayder-Beichel, K Leichsenring and V C Morris 'Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges' (2017) 26(3-4) 356.

[122] Joint Committee on Human Rights (JCHR*) Protecting human rights in care settings* Fourth Report of Session 2022–23 Report, House of Commons and the House of Lords, HC 216, HL Paper 51 para 19 (2022) at https://committees.parliament.uk/publications/23214/documents/169544/default/ accessed 29 October 2022.

this report are also relevant and applicable to children and young people in care settings'.[123]

7.06 Much of the literature concerning older peoples' care, focusses on the indignity and trauma that they experience by being denied appropriate assistance to manage their continence: by being subjected to 'pad by default' policies. A process often sanitised by the use of the term 'functional incontinence'.[124] In essence it is a system that compels them to urinate and defecate into pads (or in their beds) rather than being helped to access a commode or flush toilet.[125] It is a system for which, objectively, the justification is primarily administrative convenience and economic,[126] notwithstanding that its cost/benefits are contested.[127].

7.07 In comparison there is a dearth of literature that considers the indignity and trauma experienced by younger disabled people denied appropriate assistance to manage their incontinence by being denied access to suitable containment products. It is a system for which, paradoxically, the justification is also 'economic', notwithstanding that its cost/benefits are also contested.[128]

7.08 The data from the Cerebra survey suggests that, from the perspective of families with disabled children there is a very serious problem indeed in terms of the care and support provided by Children's Continence Services. Over 97 per cent of respondents expressed dissatisfaction with their service (or with the fact that there was no such service in their area).

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[123] Ibid, para 5 footnote 4.

[124] H Carr 'Legal technology in an age of austerity: documentation, 'functional' incontinence' and the problem of dignity' in D Cowan and D Wincott (eds) *Exploring the 'Legal' in Socio-Legal Studies* Springer (2019).

[125] M O'Rourke, Human Rights and the Care of Older People: Dignity, Vulnerability, and the Anti-Torture Norm, Oxford University Press, 2024; H Carr 'Legal technology in an age of austerity: documentation, 'functional' incontinence' and the problem of dignity' in D Cowan and D Wincott (eds) *Exploring the 'Legal' in Socio-Legal Studies* Springer (2019); R Francis *The Mid Staffordshire NHS Foundation Trust Inquiry: Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009* Volume I HC375-I The Stationery Office 2010 paras 10 – 42; and R Francis The Mid Staffordshire NHS Foundation Trust Public Inquiry Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Executive Summary HC 947 The Stationery Office (2013) see for example, para 24, 1.15, and 1.43.

[126] M O'Rourke, Human Rights and the Care of Older People: Dignity, Vulnerability, and the Anti-Torture Norm, Oxford University Press, 2024 p.174-176; H Carr 'Legal technology in an age of austerity: documentation, 'functional' incontinence' and the problem of dignity' in D Cowan and D Wincott (eds) *Exploring the 'Legal' in Socio-Legal Studies* Springer (2019); R Francis *The Mid Staffordshire NHS Foundation Trust Inquiry: Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009* Volume I HC375-I The Stationery Office 2010 paras 10 – 42; and R Francis The Mid Staffordshire NHS Foundation Trust Public Inquiry Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Executive Summary HC 947 The Stationery Office (2013) see for example, para 24, 1.15, and 1.43.

[127] M O'Rourke, Human Rights and the Care of Older People: Dignity, Vulnerability, and the Anti-Torture Norm, Oxford University Press, 2024 p.174-176; A Wimo and M Prince M (2010) Alzheimer's Disease International World Alzheimer Report 2010: The Global Economic Impact of Dementia. Alzheimer's Disease International; and L Clements, 'Social Care Law Developments: A Sideways Look at Personalisation and Tightening Eligibility Criteria' (2011) Elder Law (1), 47, 50.

[128] M Macaulay, L Pettersson, M Fader and A Cottenden 'Disposable pull-ups versus disposable nappies for children with a disability' in Nursing Times 18 May 2004 100(2).

Diagnostic Overshadowing

7.09 Children with disabilities are (as noted above – para 2.04) at greater risk of bladder and bowel complications. They are also at greater risk of these dangerous conditions not being diagnosed because their disability is often mistakenly assumed to be the cause of their continence difficulties.

7.10 Diagnostic overshadowing[129] is a phrase used to describe situations where symptoms arising from physical or mental ill health are misattributed to a person's disability leading to delayed diagnosis or treatment. It is a phenomenon that appears to be commonly experienced by people with a learning disability and autistic people.

7.11 In the course of the research programme, a parent spoke of her concerns about a young person with Down's Syndrome and a massively distended stomach. She described how this was not being 'taken seriously' and not being 'followed through': that the response from the continence service was simply to require a 'mass of ridiculously complex forms' to be completed – 'when one look at the child should have alerted the service to the seriousness of the problem'. In similar vein a parent spoke of her concerns that all too often disabled children are not provided with a comprehensive bladder and bowel assessment: that potentially dangerous conditions are left untreated which can result in long-term bladder or intestinal damage. In her case, her daughter lost her large bowel due to it becoming 'so big due to the level of constipation and bowel motility issues that were not adequately managed, leaving her with a lifelong ileostomy'.

Parent blaming

7.12 Respondents to the research surveys made several references to 'parent blame': being blamed for asking for continence containment products even when there is no prospect of the disabled child ever being bladder and bowel continent. Parents being blamed because their child is not meeting potty training milestones that non-disabled children are achieving. Parents highlighting the need for 'partnership working' rather than 'parents being blamed because they are perceived as not doing their job properly and incontinence seen as a safeguarding issue'.

7.13 A carer support organisation described how 'frantic with worry' a mother had sought expert advice concerning her disabled child's incontinence, fearing that it was due to an organic or physical obstruction and who was then blamed for wanting 'free pads'.

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[129] See for example, M Nash 'Diagnostic overshadowing: a potential barrier to physical health care for mental health service users' Mental Health Practice (2013) 17(4) 22-26 and NHS England 'Clinical guide for front line staff to support the management of patients with a learning disability and autistic people – relevant to all clinical specialties' 2023 at https://www.england.nhs.uk/long-read/clinical-guide-for-front-line-staff-to-support-the-management-of-patients-with-a-learning-disability-and-autistic-people-relevant-to-all-clinical-specialties/ accessed 20 November 2024.

Failure of accountability

7.14 As we note at para 6.17 above, of the 42 English ICBs to whom the research team sent FoI requests, 36 (86 per cent) failed to provide any information – albeit that 33 of these stated that they did not hold the relevant information[130] and referred the research team to other bodies, including NHS Trusts, councils and service providers. Only six ICBs provided details of their local policies/guidance and these revealed significant differences in terms of the eligibility criteria that they each applied.

7.15 The FoI request[131] sought basic information concerning the ICB's eligibility criteria and guidance concerning the provision continence containment products as well as details of the professionals empowered to authorise their provision. It is troubling that a large proportion of ICBs do not hold basic information concerning the continence services they are funding – suggesting, in effect, that provider bodies have carte blanche over what (if anything – see para 1.06 below) they decide to provide. Given the fundamental importance of continence services in terms of the human rights of children and their right to be free from adverse discrimination, the research provides compelling evidence of a profound failure by commissioning bodies in England.

7.16 Although not part of the research programme, in those cases where ICBs claimed not to hold the relevant information, follow-up FoI requests were made to several of the Trusts and service providers named by the ICBs in their responses. In a number of such cases the Trusts responded by referring the research team back to the relevant ICB and in one case, a social enterprise responded by pointing out that it was not a public body and in consequence not subject to the Freedom of Information Act 2000.

7.17 In contrast to the ICB responses in England all 14 Scottish HBs and all seven Welsh Boards provided a substantive response to all questions in the FoI request. Nine of the Scottish HBs (64 per cent) had adopted and applied the 2021 BBUK guidance with the remainder relying on distinct local policies/guidance which contained significant differences in terms of the eligibility criteria for children's continence support (see para 6.21 above).

7.18 In Wales all HBs stated that they had adopted and applied the 2021 BBUK guidance (see para 4.20 above) – in compliance with Welsh Government Circular WHC/2022/004 (see para 4.09 above).

7.19 What emerges from the above analysis is best described as a wholesale failure of accountability. There appears to be no current guidance, drafted by any of the three Governments concerning the provision of continence containment products for disabled children. Two English ICBs, nine Scottish HBs and all the Welsh HBs indicate that they have adopted guidance issued by an NGO, Bladder & Bowel UK. It is guidance that, in our opinion, has material ambiguities and for which significant questions concerning age and disability discrimination arise.

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[130] Notwithstanding the basic auditing requirement that a Commissioning body should have this information – a requirement made explicit in the NHS England Excellence in Continence Care: Practical guidance for commissioners, and leaders in health and social care (2018) – see para 4.04 above.

[131] See para 6.17 above and Appendix 2 to this report.

7.20 In England the position is particularly disturbing as over 85 per cent of ICBs indicate that they hold no information concerning the provision of paediatric continence care products, and the evidence suggests that in some regions no continence services have been commissioned (and in one region, at least, it is proposed that an existing service be withdrawn – see para 1.06 above). NHS England has allowed 'fit-for-purpose' guidance issued by the Department of Health in 2000 (see para 4.02 above) to be archived; has failed to publish formal replacement guidance; and has failed to mention continence care as a planning priority (see para 4.06 above). It is not fanciful to suggest that this lack of engagement has contributed to the perception that emerges from this research – of ICB indifference to the rights of disabled children to a decent continence service.

7.21 The research findings concerning the lack of accountability and the postcode variations in NHS practice calls to mind the 'chaos' to which Lord Willis of Knaresborough referred in relation to practices his Parliamentary Committee had identified in another healthcare field.[132] When addressing the Minister for Health, he added:

> You have described to us quite effectively—thank you for that—the fact there that are so many different players within this service, none of which is fully accountable for anything at all. …. throughout the country you have an array of different organisations, none of which is singularly accountable to anybody other than its local piece. Surely, it is time to do something different about it.

7.22 Given the harm resulting from the current dysfunctional system[133] of paediatric continence support services there would appear to be a compelling procedural obligation on the Governments to issue formal 'fit-for-purpose' guidance to ensure that the fundamental rights of disabled children to appropriate continence care services are provided in every region of Britain.

Discrimination

7.23 An underpinning and fundamental principle of the NHS is the obligation 'to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population' (para 3.09 above). The NHS is also subject to the specific non-discrimination obligations in the Equality Act 2010 and the Human Rights Act 1998.

7.24 As noted above, 'age' and 'disability' are protected characteristics under the Equality Act 2010 (para 3.10) and are 'statuses' afforded protection by the Human Rights Act (para 3.40).

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[132] Lord Willis of Knaresborough House of Lords, Public Services Committee, Corrected oral evidence: Homecare medicines services Wednesday 13 September 2023, Q52 at https://committees.parliament.uk/oralevidence/13633/pdf/ accessed 15 November 2024.

[133] See for example, Appendix 3 below.

Age discrimination

7.25 On the basis of the above research findings, direct discrimination on the ground of 'age' arises in two situations. The first concerns regions (in England) where a policy decision has been made not to commission any paediatric continence services but where it appears that provision has been made for adult bowel and bladder continence services.[134] The second concerns the research findings that a number of health bodies have rigid criteria that prohibit the provision of continence containment products to children under the age of five.

7.26 Although the protections afforded by the 2010 Act do not, in the context of continence services and the provision of containment products, extend to children (see para 3.11 above) this limitation does not apply in relation to the Human Rights Act 1998.

7.27 In the first situation it is difficult to conceive of a legitimate reason for denying all people under the age of 18 the essential support that they need for their bladder and bowel condition, when such support is available for people who are older than this age. In the absence of such a reason (and one that is of sufficient weight to satisfy a proportionality review) such a policy would appear to constitute unjustifiable direct age discrimination.

7.28 In the second situation, a legitimate aim would appear to be the economic cost of funding support for persons for whom incontinence is an inevitable aspect of their early childhood as well as the importance of ensuring that all children are given every encouragement to achieve bladder and bowel continence.

7.29 In assessing whether the imposition of a rigid age restriction to five years is a proportionate decision, the public body would need to demonstrate that there is an evidence-based rationale for deciding on that age. As noted above, the 2000 Department of Health guidance stipulated the age of four[135] and that the evidence suggests that by the age of 3.1 years over 93% of all children are daytime bladder and bowel continent (para 4.24). In our research we have not been able to identify a rationale or explanation for the decision to increase the age restriction from four to five years.

Indirect disability discrimination

7.30 The research evidence indicates that disabled children are more likely to suffer from bladder and bowel difficulties than their non-disabled peers: that many are incapable of achieving full continence and many will take considerably longer to achieve full continence than children who are not disabled (see para 2.4 above). 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.

7.31 It follows that a rigid policy of restricting support to all children aged five and above, is likely to have a disparate and adverse impact on disabled children. This is not, in itself, unlawful provided that the public body is able to demonstrate that such a policy is justified (and that it has undertaken a prior

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[134] BBUK Guidance p.8 and see para 1.06 above

[135] Para 4.02 above, as indeed do several Scottish HBs – see para 6.21 above.

Equality Impact Assessment to satisfy itself that this is the case – see para 3.16 above).

7.32 Given the evidence of the profound (and enduring) harms experienced by disabled children who experience bladder and bowel incontinence[136]and the impact on their families (see for example para 7.52 - 7.60) it is objectively difficult to envisage how such a rigid policy can be justified: difficult to understand why public bodies are unable to make reasonable adjustments to their policies (see para 3.15 above) by acknowledging the materially different challenges that confront disabled children; difficult understand why a policy that was acceptable in 2000 (that acknowledged that 'flexibility [in applying the age restriction] should be allowed for special cases such as children with multiple handicaps') – is no longer acceptable today (see para 4.02 below).

7.33 Demonstrating that flexibility of this kind is not justified may be especially challenging for public bodies who have adopted and applied the BBUK guidance. Problematically the guidance appears to be predicated on the misconception that it is necessary to treat disabled children in the same way as non-disabled children as this 'prevents discrimination' (see para 4.24 – 4.25 above). As noted above: (1) where the protected characteristic is disability, it is not 'discrimination' to treat the disabled person more favourably than someone who is not disabled (para 3.12); and (2) the right 'not to be discriminated against' can be violated when a public body fails to treat differently persons whose situations are significantly different (para 3.42 - 3.44).

Discrimination and the provision of continence containment products

Quantitative limitations

7.34 Over 20 per cent of the respondents to the Cerebra survey reported that they had been unsuccessful in obtaining any continence containment products for their disabled child. Of those who succeeded, over 90 per cent stated that they had experienced a limit on the number of products allocated to them. Most commonly this concerned provision being restricted to four products a day (see para 6.02 – 6.04 above). The same limit as the one cited by many of the families who have approached the LEaP programme for advice (para 1.03 above). It is also the limit specified in the BBUK guidance (see para 4.30 above).

7.35 Neither the BBUK guidance nor the other guidance we have identified, contains any research-based evidence that justifies the decision to impose a daily limit of four pads. 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.

7.36 The Department of Health 2000 guidance took this view stating (see para 4.02 above) that '[p]ads should be provided in quantities appropriate to the individual's continence needs. Arbitrary ceilings are inappropriate' and 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

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[136] See for example paras 2.03 – 2.06 and Appendices 3 and 4.

> 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.

7.37 In similar vein, as noted at para 4.11 above, the 2017 Welsh Government's guidance 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 and it does not take into account the need for a full assessment' and did not meet (among other things) its standard concerning 'dignified care'. Accordingly, the guidance stated that the 'number of products issued per 24 hours would normally not exceed four, but provision should meet assessed need.'

7.38 At para 2.122 the BBUK guidance states:

> If a CYP has an acute illness that results in a temporary increase in the number of products required, parents/carers should provide the extra products, but may require information on where/how to purchase these. This is equitable with provision for children who do not normally have products provided, but may develop incontinence for a short period of time e.g. as a result of disimpaction treatment or gastroenteritis.

7.39 The statement is troubling on a number of counts. It does not, for example, address the issue of disabled children for whom four pads are not sufficient even when they do not have an acute illness or of disabled children whose condition results in them having significantly more acute episodes that require additional pads.[137] No less troubling is its implicit assumption that 'equitable' situations are situations where everyone is treated the same, regardless of their differences (a point discussed at paras 3.42 - 3.44 above): situations determined by the quantity of inputs rather than their 'dignity' outcomes. If, as the above references in the 2000 Department of Health guidance and the 2017 Welsh Government guidance make plain, 'it is not acceptable' and contrary to the principles of 'dignity' for a child not to have adequate supplies of pads in such situations, then that presumably should be the measure of what is 'equitable'.

7.40 There may be logistical reasons why health services have difficulties in putting in place/prescribing pads for a normally continent person who unexpectedly experiences an episode of incontinence, but that would appear to be a different consideration.

Product quality and design difficulties.

7.41 As noted at paras 6.05 – 6.08 above, the Cerebra survey sought information from families as to the suitability of the quality and/or the design of continence containment products that had been provided by their local service. Over 20 per cent of respondents who answered this question stated that they had been

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[137] See for example, P Sullivan and E McIntyre 'Gastrointestinal problems in disabled children' Current Paediatrics Volume 15, Issue 4, August 2005, Pages 347-353 and S Wilson Understanding the intersection of learning disabilities and gastroenterology Royal College of Nursing 3 Jul 2024 at https://www.rcn.org.uk/news-and-events/Blogs/learning-disabilities-and-gastroenterology accessed 6 November 2024 and P B. Sullivan 'Gastrointestinal disorders in children with neurodevelopmental disabilities' Developmental Disabilities Research Reviews (2008) 14(2) 128-136.

unsuccessful in getting any support. Of the remainder (whose responses were clear) over 60 per cent had experienced an issue with the quality of the products supplied – and for these, the two issues that dominated were: (1) concerns about the poor quality of the products available, particularly the poor absorbency of continence pads and the consequential problem of leakage, as well as problems with the tab fixings such that they broke frequently or were insufficiently sticky; and (2) problems due to the 'ill-fitting' of the pads, the unavailability of 'pull-ups',[138] the limited range of products and their size.

7.42 These responses highlight the need for service 'flexibility': flexibility in the range of products available and flexibility in terms of the 'reasonable accommodations' that health bodies put in place to address the wide spectrum of disability related needs. Children with developmental disabilities who are faecal smearing and/or at risk of ingesting their faeces;[139] children with severe sensory issues who will only tolerate one specific make of containment product; disabled children who have developed mental health difficulties though the constant humiliation, the loss of confidence and self-esteem, the social isolation and the bullying that they have experienced by having to use inappropriate containment products. These are experiences that reinforce the requirement in the 2000 Department of Health guidance (para 4.02 above) that there should be:

> a range of pads available in all categories, including ... a variety of sizes/absorbencies of body-worn pads with pants, and all-in-one products for special cases' and that '[g]uidelines should be developed to aid product choice, but these should not be seen as rules.

And that:

> It is important to consider cost-effectiveness and quality of life rather than just product costs. A focus on costs alone is likely to be unsatisfactory for patients, is not conducive to treatment and will discourage companies from being creative and innovative in developing better products.

Pull ups

7.43 In relation to the difficulties that respondents referred to in accessing 'pull ups' or 'pull up pants', this may be a consequence of the BBUK guidance[140] that containment products of this kind should not be supplied (although, as we note, there is a degree of ambiguity about the guidance on this issue – see paras 4.34 - 4.41 above).

7.44 The guidance explains that the reason for the non-provision of pull ups is that:

> Studies (Simon et al 2006, Tarbox et al 2004) and clinical experience have shown they do not support toilet training. Alternative products offer similar discretion and containment and are easier to change.

7.45 The first difficulty that exists in accepting this argument, is that many disabled children are simply unable to be bowel and bladder continent. For this group, the only reason provided is that '[a]lternative products offer similar discretion

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[138] As noted at para 4.32 above 'pull ups' refer to disposable pants as opposed to nappies/pads .

[139] A D Ing, HR Roane and R V Veenstra 'Functional Analysis and Treatment of Coprophagia' Journal of Applied Behavioural Analysis (2011) 44(1): 151–155.

[140] At section 2.122 and see also para 4.32 above.

and containment and are easier to change'. This conflicts with views of many respondents to the Cerebra and the P&CA surveys as well as those who have approached the LEaP programme for advice (para 1.03 above).

7.46 The second difficulty relates to the weight to be attached to the two short papers that are cited, i.e. Simon et al 2006[141] and Tarbox et al 2004.[142] In 2021 Breinbierg et al[143] published a systematic review of the literature concerning the use of modern disposable diapers and their impact on bladder control. Their literature search identified 578 studies which after screening resulted in only eight being eligible. In relation to these, the authors concluded that a robust correlation between diaper use and continence attainment could not be established: that 'the evidence on the effect of [disposable diapers] on enuresis and [toilet training] is sparse, and it is premature to draw any conclusions'.

7.47 The 2 papers cited in the BBUK Guidance were considered to have significant limitations: the sample for one was five children between the aged of 21 and 30 months, four of whom had already undergone a toilet-training procedure, and their diapering habits were not comparable. The other study had only one participant – a 29 year old man with learning disabilities and for which his fluid intake had not been standardised.

School impacts

7.48 The responses to the Cerebra and P&CA surveys contained many distressing examples of the traumatic school experiences of disabled children with bowel and bladder conditions (see Appendices 3 and 4 below). These responses reinforce concerns that emerge from the P&CA survey and those of families who have approached the LEaP programme for advice. These difficulties often result from (or are severely exacerbated by) the inadequate and/or inappropriate containment products that are available from child's continence services. In the course of this research we have also heard of situations where schools were considering exclusion because of the child's inadequate continence products or had considered raising a formal safeguarding 'concern', simply to ensure that suitable products were made available.

7.49 As we note elsewhere in this report, parents have given examples of their child being offered minimal choice over their containment products – often very poor quality in terms of absorbency, leakage prevention, versatility and size – commonly outsized and infantilising. Many disabled children find it particularly difficult to integrate into school environments. For disabled children with bladder and bowel conditions these difficulties can be multiplied a thousand-fold: desperate to be included but acutely self-conscious because of the rudimentary design of their highly obvious containment products: of having to manage the devastating shame they experienced from constantly soiling their clothes and environments due to leakages, of smelling, of being robbed of their childhoods.

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[141] J L Simon and R H Thompson 'The effects of undergarment type on the urinary continence of toddlers' Journal of Applied Behavior Analysis (2006) 39 (3) 363-368.

[142] S. F. Tarbox, W. L. Williams and P. C. Friman 'Extended diaper wearing: effects on continence in and out of the diaper' Journal of Applied Behavior Analysis 37(1) 97-100.

[143] A. Breinbjerg, S. Rittig, K. Kamperis 'Does the development and use of modern disposable diapers affect bladder control? A systematic review' Journal of Pediatric Urology Volume 17, Issue 4, August 2021, Pages 463-471.

7.50 Research refers to children with continence problems having poor school attendance and educational attainment and 'being bullied, ostracised and excluded'.[144] In similar vein, research by Whale et al[145] refers to bullying, intimidation and social isolation that incontinent disabled children experience and the lengths that they go to, to 'conceal their problem' observing that:

> Whilst a large majority of adolescents will struggle with their identity or feel abnormal at one time or another, experiencing a continence problem creates a concrete point of difference and shame.

7.51 As we note above (para 3.37), Article 2 of the First Protocol to the ECHR guarantees the right of children to access educational institutions provided by the state and the duty is engaged where a student is denied access to a school, because of their disability:[146] that 'discrimination on grounds of disability also covers refusal to make reasonable accommodations'. In this context, the High Court has held that a denial of education can arise in a variety of ways including when an authority with the responsibility for providing education 'engages in a completely ineffectual attempt to provide it'.[147]

Poverty

7.52 The association between poverty and child disability means that disabled children in the UK are (as noted at para 2.01 above) significantly more likely to live under conditions that have been shown to impede development, educational attainment and adjustment and increase the risk of poor health, additional impairment and social exclusion'.[148]

7.53 Broach et al[149] having reviewed the data on the socio-economic disadvantage of disabled children, low income and debt observe that:

> On almost every measure of material deprivation, disabled children are more likely than other children to live in households which are unable to afford things that are generally regarded as important and ordinary for children in the twenty-first century,

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[144] Morrison, C, *Children's Continence Services in Scotland: A National Service Review* (2022) Paediatric Continence Scotland, p.33 at http://www.paediatriccontinence.scot.nhs.uk/wp-content/uploads/2022/10/Childrens-Continence-Services-in-Scotland.pdf accessed 25 November 2024.

[145] K Whale, H Cramer and C Joinson 'Left behind and left out: The impact of the school environment on young people with continence problems *British Journal of Health Psychology (2018), 23, 253–277.*

[146] *Çam v. Turkey* Application No. 51500/08 February 24, 2016 and see also This has been followed in *Enver Şahin v Turkey* (2018) 30 January Application No. 23065/12 where the Court found a violation of Article 14 with Article 2 of Protocol No. 1 on the ground that there was no possibility of suitable adjustments being made to enable the applicant (who was paraplegic) to enter university buildings for the purpose of his studies. See also *Stoian. v. Romania* (pending as at February 2018) Application No. 289/14. In interpreting the extent of this duty, domestic courts may have regard to relevant provisions of the UNCRPD and/or the UNCRC - see para 3.56, para 3.48 and para 3.45 above.

[147] *A v Essex County Council (National Autistic Society intervening)* [2011] 1 AC 280, 161.

[148] Department for Work and Pensions, 'Fulfilling potential. Building a deeper understanding of disability in the UK Today' 2013.

[149] L Clements and J Read *Disabled children: a legal handbook* (Legal Action Group 2016) at para 1.35.

such as having more than one pair of shoes, access to outside play space, participating in a leisure activity once a month or buying some basic toys.[150]

7.54 In the LEaP programme's interactions with families and in the survey responses considered in this research, many parents have referred to the severe financial hardship and poverty impacts that they experience in having to pay for sufficient and suitable containment products for the disabled child due to the absence of any (or any suitable) support from local health services. These are costs in addition to those incurred as a result of the poor quality (and/or quantity) of products: products that leak – such that that families are constantly having to wash clothing, the child's entire bed clothes, carpets, furniture – and indeed repeatedly throwing away bedding, clothing and much else.

7.55 As we note above (paras 3.53 – 3.56) the UN Committee on the Rights of Persons with Disabilities has acknowledged the reality of poverty experienced by families with disabled children and emphasised the obligations on states to ensure that in such cases disability support services are available, accessible and affordable.

7.56 The issue of 'incontinence poverty' is attracting significant concern, but predominantly in relation to costs borne by older people.[151] We have found no formal Governmental guidance in the three nations studied, that addresses the issue of the substantial additional costs many families with disabled children are having to incur as a result of the practices and policies their health bodies have in this context.

7.57 The only oblique reference to this issue appears to be in the BBUK guidance (page 16) which advises that health care professionals should ensure 'affected CYP are in receipt of any financial support to which they are entitled, such as Disability Living Allowance' (DLA). It then volunteers the information that '[s]anitary towels are not provided for girls who are menstruating'.

7.58 Many (but not all) children who are bladder and/or bowel incontinent will be in receipt of DLA: but receipt of this benefit has already been factored into the child disability and poverty data cited above.

7.59 In relation to the reference to 'sanitary towels', the inference appears to be that because these are not supplied without charge by the state, there is no reason why continence containment products for children should be. The BBUK assertion is however no longer correct. In 2021 the Scottish Parliament enacted the Period Products (Free Provision) (Scotland) Act 2021 which places duties on local authorities and education providers to make period products obtainable

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[150] Citing, C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) BMC Pediatrics 10, p21 – and observing that in some of the family surveys analysed 'substantial numbers of families report being unable to afford adequate food and heating'; and Contact, Counting the Cost: research into the finances of more than 2,700 families across the UK in 2018, 2018; and LJ Buckner and S Yeandle, Caring More Than Most: A profile of UK families caring for disabled children, Contact, 2017.

[151] See for example, Bladder & Bowel UK 'New campaign tackles 'incontinence poverty' amid cost of living crisis' January 17, 2023 at https://www.bbuk.org.uk/new-campaign-tackles-incontinence-poverty-amid-cost-of-living-crisis/ accessed 15 November 2024 and I Quarterman 'Incontinence poverty is soaring' 1 June 2023 at https://www.completecareshop.co.uk/stories/incontinence-poverty accessed 15 November 2024.

free of charge for anyone who needs to use them. In its opinion ‘access period products is fundamental to equality and dignity’[152] and central to concerns about poverty and social justice.[153]

7.60 In 2023 the Welsh Government[154] published proposals to ‘end period poverty and achieve period dignity’ asserting that ‘period dignity and period poverty are children’s rights’. In Wales free period products are available in every school and across a wide range of community venues.[155] In 2024 the English Government decided that period products should be provided free of charge in state-maintained schools and further education colleges.[156]

The inaccessibility of information concerning paediatric continence services

7.61 Information concerning the process by which individuals can obtain vital healthcare services should be accessible. It is a requirement of the NHS Constitution[157] and a core obligation of the UNCRPD.[158] In practical terms, families with bladder and /or bowel incontinent disabled children require information that explains: what support services are available in their area; what rights they have to these support services; how they can go about accessing these support services; and how they can challenge inappropriate decisions.

7.62 In relation to the issue of ‘accessibility’, the research finding concerning the actions of English ICBs and NHS England is one of wholesale failure. There is no formal Governmental guidance concerning the process of accessing continence containment products, the vast majority of ICBs do not provide accessible information on their local procedures and the responses to the research surveys (and the experiences of families contacting the Cerebra LEaP Project for advice) confirm that this vital information is generally inaccessible.

7.63 In terms of the provision of accessible information, the position in Scotland appears to be better, albeit far from satisfactory (see para 6.21 above) – a

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[152] See Scottish Government *Period Products (Free Provision) (Scotland) Act 2021: Equality Impact Assessment* 15 August 2022 at https://www.gov.scot/publications/period-products-free-provision-scotland-act-2021-equality-impact-assessment/ accessed 15 November 2024.

[153] Scottish Government *Poverty and social Justice* at https://www.gov.scot/policies/poverty-and-social-justice/access-to-free-period-products/ accessed 15 November 2024.

[154] Welsh Government Period Proud Wales Action Plan February 2023 at https://www.gov.wales/period-proud-wales-action-plan-html accessed 15 November 2024.

[155] Wels Government Press Release ‘Period products are not a luxury and access to them is even more important during a cost-of-living crisis’ vows Minister for Social Justice’ 15 February 2023 at https://www.gov.wales/period-products-are-not-luxury-and-access-them-even-more-important-during-cost-living-crisis-vows accessed 15 November 2024.

[156] Department for Education ‘Period product scheme for schools and colleges’ 9 September 2024 at https://www.gov.uk/government/publications/period-products-in-schools-and-colleges/period-product-scheme-for-schools-and-colleges-in-england accessed 15 November 2024.

[157] See para 3.08 above: the Constitution includes ‘NHS Pledges’ that it will, for example, ‘inform you about the healthcare services available to you, locally’; ‘provide you with easily accessible, reliable and relevant information in a form you can understand’; and ‘provide you with the information and support you need to influence and scrutinise the planning and delivery of NHS services’ – see the updated version of the Constitution as at November 2024 at https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england accessed 23 November 2024.

[158] See, for example, Articles 3, 4 and 9.

problem exacerbated by the lack of formal Governmental guidance concerning the process of accessing continence containment products.

7.64 Of the three nations, Welsh HBs provided the most accessible information although (as noted at paras 6.23 – 6.24 and 6.31 – 6.34 above) there were significant limitations with the quality of the information they posted on their websites. Wales is however the only nation that has official guidance – albeit that this is the BBUK 2021 guidance on which this research has expressed material reservations.

6. Appendices

Appendix 1: The Cerebra online Continence Supplies Survey questions

1. Please name your local authority.

2. Please name your local health service (for example, a hospital or a specialist children’s continence service)

3. Are you the parent carer of a disabled child?

Yes
No

4. Please state the type of impairment or condition your child has (this includes physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness and various types of chronic disease).

5. Have you encountered difficulties getting the continence products you believe your child needs?

Yes
No

6. Was there a limit on number of continence products allocated?

Yes
No

Please explain the limit in the box below.

7. Were there any issue(s) with the quality of the continence products?

Yes
No

Please explain the issue(s) in the box below.

8. Were there any issue(s) with the type or make of continence products?

Yes
No

Please explain the issue(s) in the box below.

9. Did you encounter any other issues?

Yes
No

Please explain the issue(s) in the box below.

10. If you answered ‘YES’ to any of questions 6 – 9, please could you explain the impact on you and your child in the box below.

11. How old was your child when you had these difficulties?

12. Has your local health service given you any explanation for the refusal/limitation of continence supplies?

Yes
No

If you answered ‘YES’ please provide the explanation they gave you in the box below.

13. If you experienced any difficulties getting appropriate continence supplies for your child, have you complained to your local health service?

Yes
No

If you replied ‘yes’, please detail the outcome in the box below.

14. If you have any other comments you would like to make please detail them in the box below.

Appendix 2: Copy of the Formal Freedom of Information Request sent to local Integrated Care Boards and Health Boards

Formal Freedom of Information Request

Dear

I request that you provide the following information in compliance with your duties under the Freedom of Information Act 2000.

The purpose of the request
I seek the information detailed below in order to better understand the process by which disabled children and disabled young people living in your Board's area are able to obtain the Integrated Care Board funded continence pads and containment products that they need.

Statutory cost compliance limit note
If your Board considers that complying with this request in its entirety will exceed the statutory cost of compliance limit (specified in The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004) then I ask that you respond to the following requests in the order they appear until that limit is reached.

Requested Information
Please provide the details specified in (a) - (c) below concerning the provision of continence pads and containment products (including nappies and 'pull ups') for disabled children and disabled young people within your Board's area.

a. The eligibility criteria that determine what type and what quantity of continence pads and containment products can be provided for disabled children and disabled young people.

b. Please provide a copy (in printed or electronic form) of the guidance that your Board requires practitioners to have regard to when authorising the provision of continence pads and containment products for disabled children and disabled young people; and

c. The work title (or post or qualifications or other designation) that identifies the practitioners who can authorise the provision of continence pads and containment products for disabled children and disabled young people.

I understand that under the Act I am entitled to a response within 20 working days of your receipt of this request.

If this request is denied in whole or in part, I ask that you justify all refusals by reference to specific exemptions specified by the Act.

If you require any clarification, please contact me via email at [Student's University email] in accordance with your duty under section 16 to provide advice and assistance if you find any aspect of this Freedom of Information request problematic.

Please acknowledge receipt of this request by email. I look forward to receiving the information in the near future.

Appendix 3: Summary of findings about trauma from the online Cerebra Continence Supplies Survey

- His skin suffered rashes. (Response no. 2)
- We spend a fortune on nappies. (Response no. 3)
- We do not get any support at all, so feel alone with all. (Response no. 5)
- Just added stress. (Response no. 6)
- Stress, unnecessary expense, frustration, zero face to face until I received the products… If my daughter can’t even answer to her name how on earth is she to potty train. So awful. (Response no. 10)
- We stopped using the service completely due to the low quality and lack of appropriate products available. We now have to buy our own [products] at supermarkets at our expense. (Response no. 12)
- Constantly soiled clothing and bedding, sore skin, huge amounts of additional laundry. Got to the point where we hardly left the house because of incontinence and leakage. (Response no. 15)
- We have been made to spend so much money just to let our son go to the toilet hygienically and with dignity. It has had a huge impact on our lives. I had to give up work initially to care for my son and go through all the issues getting diagnosis etc and then to have to pay this on top of an already difficult situation is scandalous. We are paying huge bills for washing and drying too as incontinence means soiled clothes and bedding – especially as he strips too due to sensory issues and autism (Response no. 20)
- My child is uncomfortable in the nappies, often pulls them off, soils himself. (Response no. 24)
- Endless phone calls trying to contact nameless individuals, who can make decisions regarding qualifying for continence products unsuccessfully. Enormous expensive self-funding. Difficulty sourcing appreciate size etc. (Response no. 27)
- Cost and absence of suitable available pads. (Response no. 28)
- Paying ourselves when other get provided. Lack of support and understanding. (Response no. 29).
- Nurse needs chasing up multiple times whenever a change in size/type/ratio is needed, as she ignores messages. (Response no. 30)
- My child’s skin was in a terrible state – huge blisters from poorly fitting pads, and no-one would take responsibility for prescribing new ones. (Response no. 32)
- Three pads for 24 hours is nowhere near enough for her routine and her hygiene… I don’t know what we will do if we are restricted to 3 for 24 hours (Response no. 37)
- Impact is huge when we have not got enough pads to deal with an upset stomach eg diarrhoea or times when daughter needs to drink more in the summer. Pads leak as they are not designed to hold huge amount of urine. We have more washing which is costly with high energy prices. We have to buy top ups of pads in between every delivery, which is costly. Surely it infringes human rights to limit a person to 3 toilet visits per day? (Response no. 38)

- My child is still in nappies, we are financially struggling very badly. After a long time when support provided that wasn't suitable at all and they said we can't do anything. (Response no. 43)
- Lots of frustration from both my son and myself, lots of underwear being wasted and thrown away and not washable. (Response no. 46)
- I had to buy extra pads to ensure I could change him regularly. As he is fed via a jejunostomy he has very loose and frequent stools which needed to be changed immediately to prevent infection and skin breakdown. (Response no. 49)
- Cost implication. We are reliant on UC [Universal Credit] – yet still have to cover all additional costs. (Response no. 53)
- We are having to buy adult incontinence products, but they are too big. But children's nappies are too small. (Response no. 54)
- Poor quality products available. I have only found 'DryNites' which fit OK but don't keep her dry for long. They leak. (Response no. 55)
- On days where she is on antibiotics and needing more frequent changing, we often run short [of continence supplies]. (Response no. 58)
- I'm not in a position to purchase additional products and I believe that we would have serious problems if they reduced his allowance. The impact on myself is huge. The phone calls you have to make, the arguments you have trying to justify your child's needs. The stress it creates really starts to affect your mental health and I still vividly remember bursting into tears with frustration the last time they tried to cut his supply. (Response no. 59)
- Financial impact – had to buy products for a full year, after we were entitled to free ones. And still buying supplementary products as the service offers 'a contribution towards the child's needs' – rather than meeting the need in full (Response no. 60)
- Every time my son passes urine he floods so needs a complete change of clothes. This isn't good for his skin or his dignity and it's terrible for my washing machine. I can do in excess of 5 loads of washing a day some days if he leaks in bed. (Response no. 61)
- [My daughter] Thinks she is a baby. (Response no. 63)
- We've intentionally kept her in nappies that are too small as the next size up available to us is massive – not good for a child in a mainstream school for her dignity. (Response no. 66)
- My child struggled throughout year 4-6 in primary school. As a result… they struggled to make friends and their education was challenging for them. (Response no. 69)
- When she has accidents, she is bullied as she smells as only has pants. (Response no. 73)
- My son will probably never be fully toilet trained, but he has no chance of gaining any independence around toileting while not in pull ups. The pads supplied are ill fitting and not suitable for my son. He regularly uses one hand to support his crotch as the pad hangs down and he can feel it, which he struggles to tolerate due to his sensory issues. He then struggles to engage in learning at school because he only has one hand free, and is preoccupied with his pad. We are having to buy pull-ups when we can afford them, to try and support him while in school. For the Local Authority to insist on supplying a product that is not fit for purpose, and one that

denies a child the right to a level of independence is inexcusable! (Response no. 75)

- I have also not always changed when only a bit wet due to our limit of 4 per day. (Response no. 76)
- It made me depressed. (Response no. 79)
- Our carers refuse to use them even in emergencies as they are so unsuitable. (Response no. 81)
- My son was in pain. (Response no. 83)
- These pads need to be changed so frequently that it impacts on the user's ability to have a prolonged period away from the home. We no longer go on day trips. (Response no. 86)
- I have had to buy extras which don't fit properly as my son regularly uses more than 4 a day, especially when he has an upset stomach. I will not leave my child in a soiled nappy… it causes him to get severe nappy rash. (Response no. 89)
- We were never allowed to access continence products. (Response no. 90)
- This meant the pulls up we have either are too tight on him, or he has a wet bed every night, leading to [him being] dysregulated and losing his confidence. (Response no. 92)
- Very stressful worrying about not having enough pads, especially as disabled kids are ill more often and have diarrhoea more often but you still get same number of pads each time! Other parents have same problem - if lots of carers can't get the situation changed you worry even more that professionals won't listen to you. It all adds to the stress especially for PMLD kids as you have to juggle so many services and appointments the last thing you want is worry about lack of pads, lack of adapted toilets, and not being able to go out anywhere as there is nowhere to change your growing child/teenager/young adult! (Response no. 96)
- It has added to the other barriers to going out and about and maintaining her sit to stand ability. Carers supporting her found sit to stand too difficult using nappy product so her days out are cut short so she comes home to use the change bed or hoist or she is limited to going where there are changing places facilities with her carers. (Response no. 98)
- It is cruel and abusive to leave them in wet soiled pads. (Response no. 101)
- Difficult to find the right products. (Response no. 103)

Appendix 4: Summary of findings about trauma from the P&CA Continence Supplies Survey

- We have been told we cannot access nappies on the NHS as she is only in them at night despite her having special padded pants and accidents in the day.
- Was told if he can control his bladder he can control his bowel.
- Our five-year old is a very heavy wetter who voids over 2 litres a day. For context, he weighs 16.5-17kg. 4 nappies per day isn’t enough. He goes through 10-12 per day. The delivery interval is every 16 weeks. For the current size that would be a delivery 1.5m cubed. Who has that amount of spare space? Why not monthly deliveries? That would be more manageable, but I guess the idea is to put people off, have them buy their own instead.
- We were told that the continence team would not help with nappies until our child was 5 and then the nappies are quite big and you only get a few per day…
- … school nurse raised concerns about daughters continence needs but was unable to refer to the continence nurse as our gp was cross border.
- Gave up as son wouldn't Swallow tablets continence nurse insisted he try first before prescribing continence nappies. He also reacted to nappies used in hospital so we ended up buying tena flex on ebay as we knew he didn't develop blisters using them.
- Was told don’t qualify for only night time wetting.
- Very poor service. Nurse refused to order the needed appropriate size pads and pants of patients choices. Patient needed back coloured disposable pants but nurse Refused to order those instead she ordered massive big all bads wrong size and wrong size bad quality disposable white pants -adults with incontinence have bad problems too.
- NHS changed supplier to an inferior product. Reduced the choice of what was available (nappies, pants, pads, sheets). Reduced the number allocation per 24 hours down to three per 24 hours of only one product (stopped being able to get so many packs of nappies AND pads).
- Our first experience was terrible and awful that I wasn’t able to call back the service again. My husband did eventually call back and had a much better experience and we were able to finally acquire pull ups for our child. My first experience I was told he wasn’t eligible for free nappies even though he was and that they couldn’t give him bigger nappies or pull ups unless he was potty training. My child is quite tall for his age and his bed wetting was and still is daily. Nappies are not sufficient for him and we need pull ups. I explained this and still was told the same. I felt like I wasn’t being heard and it made me feel frustrated as I wasn’t being difficult. This was my child’s situation and it seemed like there was no care or consideration for it.
- Waited two years – no new info/support then given. As night only an issue – no products provided.
- as much as the advice pages are good for some children, it does not considerate disabilities for children such as [name], who’s have [sic] profound learning disabilities and delays which would mean they would never be able to follow any of these steps. He cannot read or write so this information sheet for children such as my son is incredibly ableist.

- Health visitor referred us, but apparently you have to show “sustained evidence you have tried potty training”. Not sure quite how they expect to see this evidence from a non verbal child with gdd, asd.... But that’s where we are!
- My son is 8 with quad cp, double incontinent and we’ve never been told of them or of any help surrounding this…
- … and have been lucky recently there is a lady in [name of town] who they repeatedly deliver the wrong size to (about 1 in 3 deliveries) then replace but never do a pick up so I pay her £30 for 3 packs rather than 27 per pack and she donates it to the air ambulance…
- We’ve been accepted but have been told it will be months if not years before we’ve been seen… They don’t accept referrals for under 5. ASD, GDD, SPD visually impaired.
- The aim a lot of the time seems to be typically neurotypical in approach… it’s frustrating and not enough understanding that our children are who they are and no matter how many charts, parenting adaptations are made, they’re not going to just be able to start using a potty or toilet…
- … unfortunately with Continence, you have to threaten legal action as I battled them for years too. They only wanted to provide 2 nappies per day for a young person who went through at least 6 per day and doubly incontinent at the time. Obvious complex disability and it was still argued. We did buy our own whilst fought them and won.
- It cost us a lot whilst we went back and forth. At £12-£15 per pack etc. We still buy all the baby wipes cleaning stuff etc, as although very recently out of products this year physical age 17, still many accidents.
- They wanted my son to use pads, which was not age appropriate (he was five, but a big lad, so the offer for his age did not fit). Then they suggested nappies, which I felt was a backwards step for him as he had mote potential for independent toileting with pullups.
- I have a 14yr old who is doubly incontinent… No progress has been made at all. My son wears pull-ups day and night and we have never been offered pull-ups or nappies or any other meaningful help. I spend a small fortune on pull-ups - help with supplies would have been/would be amazing but I don’t have the time or energy to fight for it. I don’t have the best opinion of the advice/“help” we received from the community continence service – they didn’t seem to know what to do with an autistic child with continence issues. All their advice/techniques seemed to be more fitting for neurotypical children who wet the bed at night/need basic toilet training.
- We couldn’t get a referral – we were told to self refer to the school nurse but because he emotionally isn’t ready for toilet training she discharged him. He’s 6 and has cerebral palsy and currently refuses to even step into the toilet at home. All the questions and resources seemed to be aimed for neurotypical children and those without a physical disability.
- … try all avenues offered then you’ll have lots of evidence to show you need help.
- Honestly it just goes to the bottom of my list as always working on other things that are more pressing with a child with complex health needs.
- We’ve been told to wake her up in the night to put her on the toilet despite us saying that she has a lot of sleep medicine as she doesn’t sleep well! This would also require hoisting so we would all be up for a long time. No way would we wake up a child who has to have sleep meds!

- He seems to have so many issues with being out of pull ups I leave him in them (at quite an expense obviously!) to avoid him being out thru any hoops. I get so worn out going thru services I just put that one to the bottom of my to do list…
- My son has had bowel and bladder issues since he was 3 (he’s now almost 8) and it took us until he was 5 to actually get referred to Bowel and Bladder. … I did manage to get pull ups on prescription but this took me a long time to get them to agree to this despite my son wearing them 24/7.
- Many of these children do not undergo a comprehensive bladder and bowel assessment. If families are "lucky" they can obtain access to a simple “pad assessment” and are issued with nappies in the mistaken belief that they are not ready to be toilet trained. This is a potentially dangerous situation, particularly as untreated problems can lead to long-term bladder or intestinal damage.
- My daughter lost her large bowel due to it becoming so big due to the level of constipation and bowel motility issues that were not adequately managed leaving her with a lifelong ileostomy.
- We must challenge the view that disabled children's families only want pads from the continence service due to cost. If pads are required then the correct product is essential to prevent soiling of furniture and surroundings and the additional risk of infection that can come from this.
- My daughter had just started at her new primary school. She had been moved schools as her needs were not being met at the previous school. The new school was really welcoming and far more inclusive. For the first time I thought that I could leave the local area, and pop into town and buy myself a new coat whilst she was at school.
  Almost as soon as I arrived, I received a phone call from the school to say that I needed to collect my daughter from school as she had an a "accident". What they meant was that she had a stoma poonami! After getting stuck in traffic, I arrived at the school to hear my daughter screaming. As I rounded the school and came into view of the playground, I saw my daughter being prevented by three staff to get out of the Little Tikes red car that she had been playing in. She had been left soiled and then trapped for over two hours before I could get to her. The incident caused so much trauma because the staff did not have sufficient training to manage the higher-level continence issues nor given any thought to how my daughter may be feeling. They didn't want to deal with her. This incident caused long term and significant school-based anxiety around the possibility of having a leak and absolutely broke my heart.