CHILDREN'S CONTINENCE SERVICES IN SCOTLAND: NATIONAL SERVICE REVIEW

Paediatric Continence Scotland

Dr. Catriona Morrison
Tayside Children' s Hospital
Dundee DD1 9SY
E-Mail: catriona.morrison3@nhs.scot

July 2022

Executive Summary

Paedatric Continence Scotland (PCS) was founded in September 2020 in response to the recognition of the need for better continence services for children in Scotland, and to provide a network for clinicians from all Health Boards in Scotland who care for children with bladder and bowel dysfunction and continence problems. PCS was aims to provide a supportive professional network, training and education, and to act a lobbying 'voice', advocating for better services for children with Bladder and Bowel Dysfunction and continence issues in line with guidelines for best clinical practice as set out by NICE (ref 1) and ICCS (ref 2).

Two years on, PCS has held 4 biannual well attended study days, offering basic and advanced training. We continue to work with the Children and Families Directorate around national provision of children's continence services, the role of Health Visitors (HVs) in promoting bladder and bowel health in 0-5's and best practice for toilet training. The role of School Nurses (SNs) has also been questioned: their withdrawal from provision of clinical care for nocturnal enuresis, without any provision of alternative workforce, left large gaps in service in many areas. Scottish Government commissioned and published an e-Module on Bladder and Bowel Health in Children in 2020 as part of their response to the recognised need for improved training and services.

This report sets out the findings of a National Review of Children's Continence Services in Scotland, conducted at our June 2022 study day with written submissions from all 14 Health Boards. 207 clinicians attended this event in total, 150 of whom provided a range of feedback on specific questions about children's continence services in their area. *Appendix 1*

This report confirms that the provision of children's continence services in Scotland remain extremely variable and generally under-resourced, with chronically poor staffing in many areas. In some, there is no functioning service at all. Most areas do not provide an integrated model of care whereby children can access all their continence needs within one service, resulting in inefficient use of already limited resources, delays in patient referral and care and increased clinical risk; this contributes to the inappropriate and expensive use of continence products. Child protection and neuro-developmental problems are common in this population and require specific, skilled management which demands extra resources. There is no post-graduate training programme for Specialist Paediatric Continence Nurses, training for level 1 and 2 health professionals is ad hoc with no specific funding and is variable across Health Boards. There are, however, many examples of excellent practice to be found within this highly committed and dedicated group of clinicians, and a few Health Boards which have been more supportive in developing their children's continence services.

This report will consider the current costs of care for children with bladder and bowel dysfunction and continence problems. It will also provide analysis and comment on the requirements for cost-effective, equitable Children's Continence Services in Scotland.

Background

Continence problems occur from infancy through childhood into adolescence and beyond; they include difficulties with toilet training, bedwetting (enuresis), daytime wetting (DUI), constipation and soiling. These conditions often start in pre-school years, are common, distressing, stigmatising, under-treated and under-reported. Often, they are over-looked and wrongly attributed to being 'developmental', or worse, 'inevitable' in the case of children with disability. It is estimated that 1 in ten children (Ref 3) are affected by incontinence, equating to 115,000 Scottish children; although with up to 30% of children also suffering from constipation, this is likely an underestimate. (Ref 4) Treatment includes both medication and behavioral modification, as well as other modalities and is often required for many months or years, with over a third (Ref 5) of children developing chronic problems that frequently persist into adulthood with long-term costs to the health service: ¼ of children with constipation continue to have symptoms as adults. As one teenager described of continence problems: "they aren't life-threatening, but life-ruining".

Bladder and bowel dysfunction very frequently co-exist, necessitating an integrated, holistic approach to treatment which is only possible in the context of clinical services that are integrated. Most services in Scotland, however, offer separate clinics for bedwetting, delayed toilet training (if at all), daytime wetting and constipation/soiling, with 10 of 14HB's relying on totally separate services for the provision of continence products. Although most children with bladder and bowel dysfunction can acquire continence with the right support, poorly treated continence problems may lead to recurrent UTI, kidney scarring (Ref 6) and lifelong bladder (Ref 7) and bowel (Ref 8) dysfunction and impact negatively on mental health (Ref 9) and educational attainment (Ref 10). Rarely, children may die from gross faecal impaction (Ref 11) Sub-standard assessment of continence problems may lead to children being inappropriately given continence products (pads, pull-ups, nappies) instead of being treated adequately for bladder and bowel dysfunction and becoming independently continent. (Ref 12)

Adult continence services are easily accessible and exist in every health board in Scotland; most have access to multidisciplinary team working. By contrast, where they exist, children's continence services are often fragmented, poorly organised and signposted, and are significantly under-resourced. The lack of adequate services leads to delays in treatment, chronicity and poor outcomes at high cost with carry-through costs in terms of adult continence care.

The updated 'Paediatric Continence Forum (PCF) Commissioning Guide" (Ref 13) has been widely endorsed by continence advisors, school and community nurses and Health Visitors (ACA, BAPCUN, CPHVA, SAPHNA) as well as the RCN and the RCPCH. It stipulates that all children's continence services should be nurse-led (with medic support), integrated, offer the full range of children's continence care (including assessment for and provision of continence products) and should be led by a Band 7 Paediatric Specialist Continence Nurse. The current PCF recommendation of 1 WTE nurse per 10,000 children is under review and will be upwardly adjusted in the updated 2023 edition of the guideline, due to demographic shifts and increased numbers of children with disability. (Personal communication)

Continence service provision was debated in Scottish Parliament in 2017 (Ref 14) (albeit with a definite focus on adult needs) with agreement around the importance of adequate continence services. This led to an exhortation from the Chief Medical Officer in 2018 (Ref 15) to all Health Boards requesting that: “everything possible be done to improve care and support to people [this should include children] with continence issues, including preventative measures” In addition, a submission around the lack of children’s continence services and the attendant clinical risks was made in 2019 to Shona Robson, the then Health minister, by the author and others.

For children with bladder and bowel dysfunction and continence problems, this means:

- appropriately resourced bladder and bowel services in the community that are integrated and therefor efficient and cost-effective, and will improve quality of care and quality of life for children with continence problems and their families
- the need for early identification and management of continence problems as well as early support and advice for toilet training, which will reduce the likelihood of bowel and bladder problems later in childhood and the need for use of continence products: this is good practice in terms of care and spend
- support for children with additional needs from the first year of life which is essential for them to reach their ‘continence potential’ and avoid unnecessary reliance on expensive continence products
- a well-trained, skilled workforce, with training for all staff provided by the specialist nurse-led, community-based Children’s Continence Service
- children’s continence services must be inclusive of all ages 0-19, and provide tailored, individual care to all children including those with disability
- transition arrangements must be put in place to facilitate a well-organised, planned move from children’s to adult services considering individual needs

  pathways between generic services, specialist continence teams in the community and secondary/tertiary care must be well mapped out and accessible

Despite the clear need and the evident lack, there is still no national mandate for the provision or structure of children’s continence services in Scotland. With a national strategy in place for Children’s Continence Services, we believe that health outcomes will be significantly improved, clinical risk reduced and spend on continence care will overall be less.

The costs of children’s continence care in Scotland

As services currently stand, they are costly and provide poor value in many HBs:

- Continence products: estimated national spend of 1.45 million; precedent of 50% savings once an integrated children’s continence service is in place (Ref 3) prevention, early intervention and timely continence care will reduce product use

- Costs of medication, medical care and continence products of unresolved continence issues that project into adulthood good continence care throughout infancy, childhood and adolescence will reduce chronicity of incontinence with attendant savings

- Chronic kidney disease and renal failure may result from poorly treated bladder and bowel dysfunction. A renal transplant will cost upwards of £142,000 over 25 years Better care for bladder and bowel dysfunction will avert catastrophic health outcomes for the child and financial consequences for the NHS

- GP and paediatrician pathway for a series of appointments and investigations £461 per child, compared with specialist nurse pathway £85.50 (Ref 16) Investment in a nurse-led service avoids inappropriate and unnecessary doctor-led continence care

- Unplanned care costs – in one year alone, 11,093 admissions to hospital for constipation for 0–18-year-olds in the UK, at a cost of £1838 per day (Ref 17) providing children’s continence services with a well-trained, skilled workforce has been proven to reduce hospital admissions for constipation to almost zero

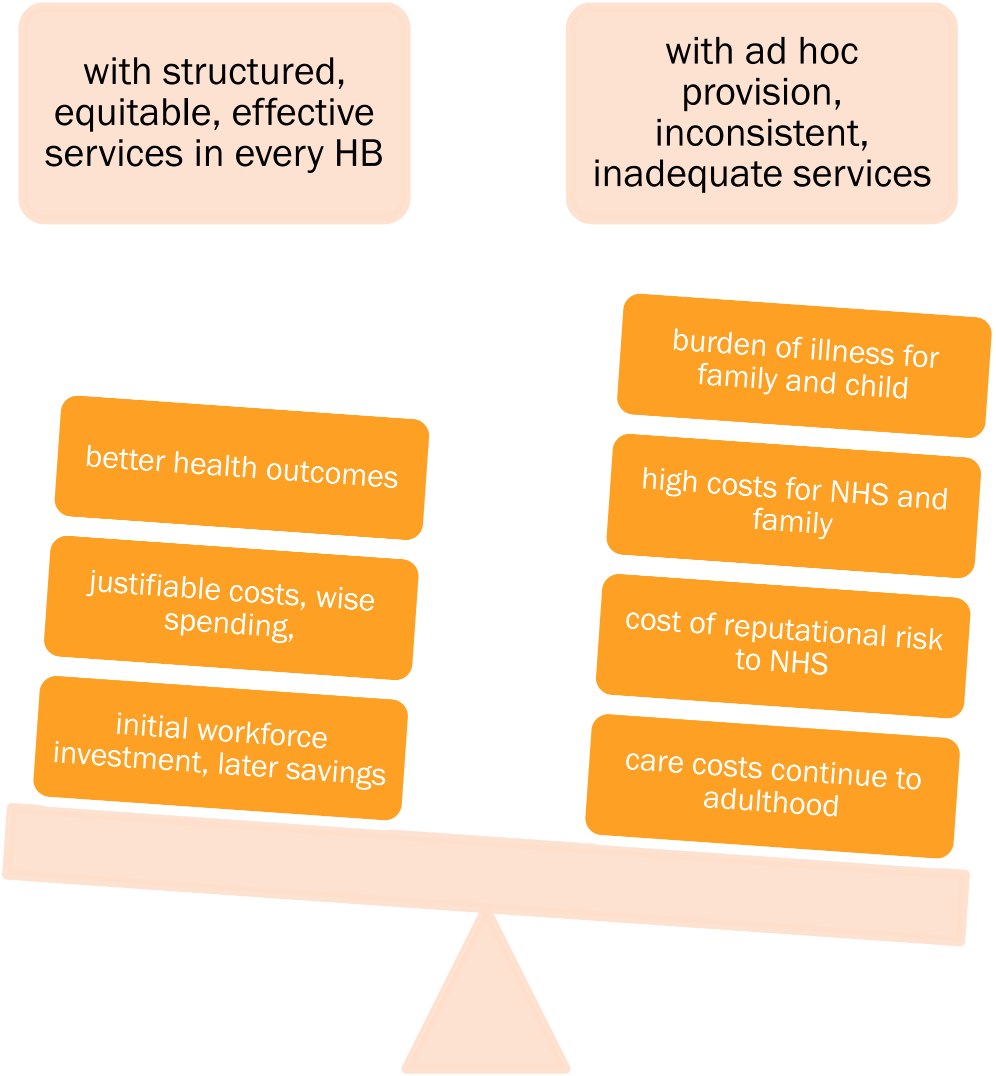
- Scheduled admissions to the children’s ward for disimpaction, intensive toilet training, £1836 per bed day; this can be virtually eliminated with better early intervention from community based, accessible services (Ref 3, 17)

- Daycase admissions for disimpaction, intensive toilet training £554 per day these are mostly avoidable where children’s continence services have been properly developed and maintained

- Investigations: abdominal ultrasound, abdominal X-ray, uroflow studies, bladder scanning, nuclear medicine kidney scans, spine MRI: unquantified use of more complex investigations will be less with better, earlier continence care for children with improved patient outcomes; bladder scanning is an inexpensive tool that can easily be used in community-based, nurse-led services

- Medication costs: laxatives, suppositories, anticholinergics, desmopressin provision of the effective, immediately accessible children’s continence care will allow reduction in medicines use, due to the impact of early intervention reducing the chronicity of bladder and bowel dysfunction

- Persiteen transanal irrigation: £1820 per year per child for children with refractory constipation and soiling can spare the child a complex surgical procedure such as ACE with its associated in-patient care, anaesthesia and surgery costs as well as ongoing care; transanal irrigation can be delivered in the community by a nurse-led service and allows for flexibility of use as recovery ensues



This diagram represents the contrast in approaches to providing children's continence services; currently in Scotland we have a situation of ad hoc service provision with the attendant costs and poorer outcomes. The alternative model of a planned framework of structured services nationally, offers improved outcomes at lower long-term cost.

Here are the 2021 updated costs from one medium-sized HB (population of just over 400,000)

Service Area	**Unit cost**	**Units p.a.**	**Annual Cost**
Consultant appts	£291	1500	435,000
Day case	£1105 per day	120 days	132,600
A+E	£135	Ave 1 - 2 per month	2, 000
Ward Admission	£1989 /day	Average 96 days	190,944
Continence products	Variable per unit	410 patients	106, 472
Persiteen trans-anal	£1820/ year	28 patients	50,960
Specialist Nurse B6	£56 per appointment	Total 2,530	141,680
Enuresis Medication	variable	Summary costs	103,376
Uroflow studies	£220 per study (NHS England)	210 p.a.	46,200
Total costs for one HB			**1,209,232**
Projected national costs			**16,566,478**

Scaled up to represent the total population of Scotland, this translates into an **annual spend of over £12,500,000**, based on the expected consistent population prevalence of continence problems and product provision. This spend is on a model of service delivery that is severely under-staffed resulting in long waiting times and large caseloads, and fails to deliver a consistent, acceptable level of care for children across Scotland.

Savings: Improved Children's Continence Services

Over a period of 5 years from establishing an integrated children's continence service in Liverpool, referrals of children with functional constipation to secondary care were almost eliminated (currently 25-30% of our consultant paediatric clinic appointments are for bladder and bowel dysfunction) saving over £250,000 p.a. The same area saw the use of products drop from 700 to 300 children per year, reducing the budget for products by 50% (Ref 3)

A similar reduction in costs applied to the example HB above would result in the following savings:

Efficiency	**Savings**
Reduce dependence on general paediatric clinics, 1/2 consultant appointment costs	217,500
Reduce/remove the need for CIU and Ward Admissions by effectively treating as OP	323,544
Reduce by half, based on PCF study, use of continence products	53, 000
Impact on Persiteen use	15,000
Total projected example HB savings	**594,044**
Scaled projected national total savings	**8,138,402**

When scaling this up to project savings nationally, after establishing a structured framework of children's continence services, conservatively anticipated **savings would be over £8,000,000.** This does not include savings from medication, the reduced need for investigations or the reduced need for using GP appointments as the more expensive replacement for a nurse-led service.It also does not factor in the savings over lifetime use of containment products, which for adults are more costly than for children. Adults with disability now have improved survival, and over a lifespan of 50 – 60 years the spend per individual could amount to £98,640 (ref 18)

The following are illustrative, anticipated investment costs of the new model of integrated children's continence services, led by a Band 7 Specialist Continence Paediatric nurses, and supported by a mix of skills level within the team to approach the minimum of WTE staff numbers of 1 per 10,00 children in each HB.

Additional Nursing Staff	Unit cost p.a.	Number	Cost
Band 7 Specialist Nurse	£40,000	12	£480,000
Band 6 Specialist Nurse	£33,000	21	£693,000
Band 5 Nurse	£26,000	30	£780,000
Band 4 Nurse	£24,000	30	£720,000
Total		**93**	**£2,673,000**

Workforce investment needed to achieve recommended staffing levels

The table below summarises the potential financial impact of improving Children's Continence Services across Scotland. Delivering the shortfall of 93 nurses in children's continence services nationally could deliver over **£5 million savings.** Given the undocumented costs of, and impact on, medication use, medical time and investigations, this is likely to be an under-estimate.

Projected current national costs of continence care for children:	£16,566,478
Projected national savings for children's continence care with improved service provision	£8,408,132
Workforce investment spend	£2,673,000
Remaining savings from children's continence service improvement	**£5,735,132**

The Lancet reported in 2019 that the annual costs of constipation alone to the NHS included £91 million on medication, 196 hospital admissions per day and 218,000 GP appointments p.a. (Ref 19) One in three children suffer from constipation and it has been shown that 25% of children will continue to have symptoms into adult life, which strongly correlates to delay in starting treatment. (Ref 20) Inadequate continence services for children results in symptoms becoming chronic and expensive for the NHS over the entire life span.

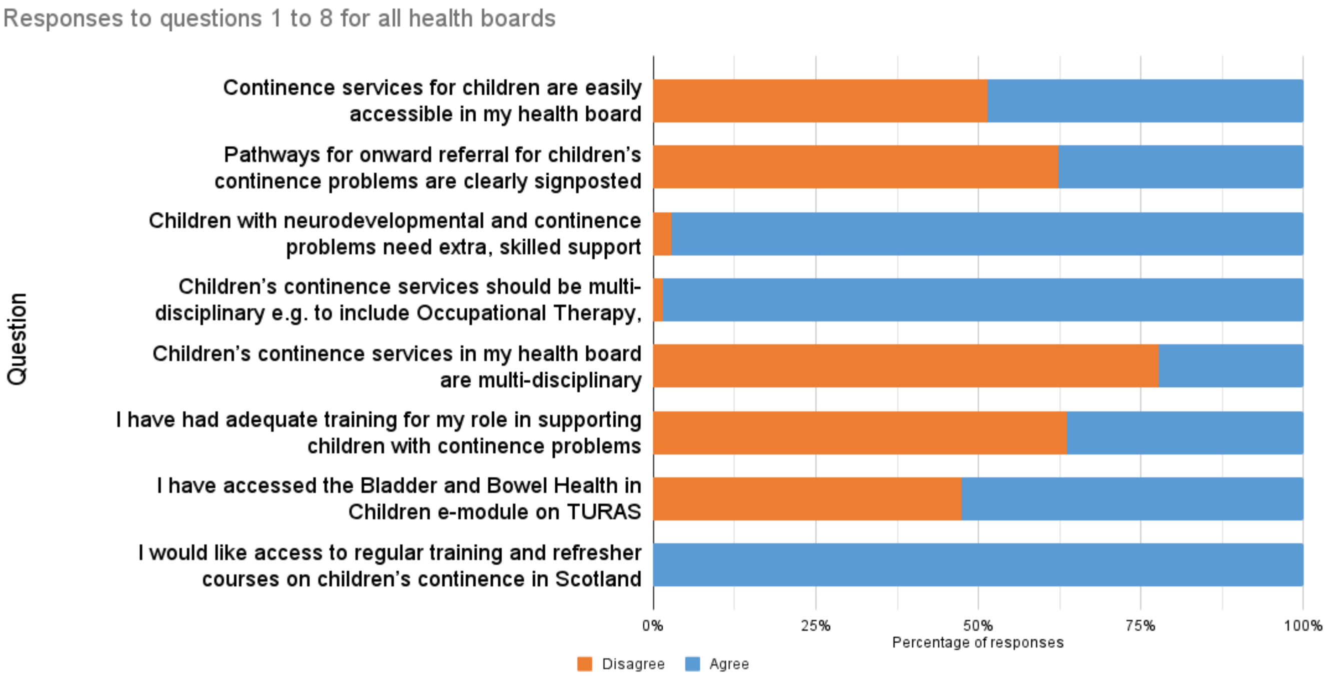
By investing in training and an improved, skilled workforce with designated, accessible children's continence services care can be given 'in the right place, at the right time, by the right person'. *appendix 4*

This will deliver a service which is patient -centred, supports GIRFEC and SHANNARI principles *appendix 2* and will produce improved patient outcomes at lower cost. This investment in children's continence services will carry through to adult services, in terms of reduced lifelong product use and adult continence service demand.

1. Current state of Children's Continence Services in Scotland

1.1 Access to services and training

The limited accessibility of continence care for children in Scotland is illustrated in the graph below. It reflects the poor level of provision in many areas. Health professionals in different HBs have very varied levels of training, knowledge, confidence and responsibility for delivering continence care, and are often operating in a 'make do' working environment with highly variable access to the resources needed to provide adequate services. 150 individual feedback forms were received following the Study Day and showed that:



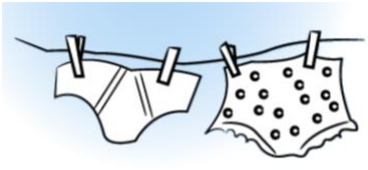
- only 48% described services as easily accessible, with 60% saying pathways for onward referral were unclear.

- 97% agreed that children with additional neuro-developmental problems need extra, skilled support. Children's continence care differs significantly from adults, necessitating a child-centered approach appropriate to their developmental, psycho-social and physiological needs.

- 98% felt that children's continence services should be multidisciplinary, with access to other allied health professionals and CAMHS,

- only 28% reported that services in their HBs were multi-disciplinary

- only 52% had accessed the e-Module on Bladder and Bowel health in Children in the past 2 years; it is difficult to imagine that parents and educators have been able to access it (which was the original intention) given the limited uptake of those working within the NHS



- 77% felt their training was inadequate- even though this was a group of clinicians with much higher levels of training in children's continence than other health care professionals

- 100% wanted access to regular training.

In the updated PCF Freedom of Information report 2021 on provision of continence services in the UK, (Ref 21) Scotland is an outlier in terms of:

- falling levels of provision of integrated paediatric continence services since 2014 when the first survey was carried out: see note*

- the least number of services led by a specialist paediatric continence advisor

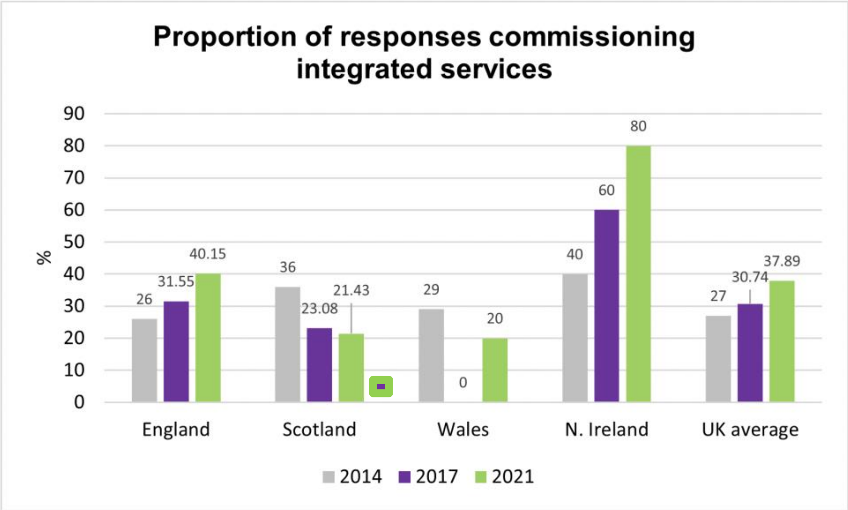
- the second worst levels of staffing compared with in relation to caseloads with 1.31 WTE per 586 children, just ahead of Wales with 1.16

- just 21% of Scottish HBs planned to review their existing continence services for children

- Scotland had the lowest level of awareness and use of the PCF commissioning guide document by a significant margin

Question 2a: Is there a single (integrated) service for all the above five problems?

Figure 2



*Note: updated information obtained in this report indicates that only 1 of 14 HBs in Scotland has a truly integrated children's continence service, equating to 7% and not 21%, the lowest by far in the UK 🟩

1.2 Funding/Commissioning of Services

- Budgetary constraints are frequently cited as reasons why children's continence services cannot be put in place or improved. A nurse manager commented "there's no money for our service" but also remarked: "daytime wetting [cases] go straight to the paediatricians" and from a nurse in a large HB: "Children with constipation are dealt with by GPs who refer on to paediatricians or paediatric gastro-intestinal surgery" However:
    - Community based, nurse-led services are cost-effective and relatively cheap in terms of affording comparable care to community/secondary care, doctor-led services.
    - They reduce wasteful expenditure by preventing A+E attendance and hospital admissions, reducing repeated GP visits and reliance on expensive consultant appointments in secondary care.
    - An integrated nurse-led service allows for related bladder and bowel conditions to be efficiently treated together, avoiding the need to provide multiple different clinics addressing different parts of the same problem. (Ref13)
- Without any clear government policy on provision of children's continence services, HBs are not answerable in terms of providing a specified level of service. In 3 out of 14 HBs, this has resulted in there being no designated service. 10 of the remaining 11 that do have a designated service have a fraction of the minimum staff requirements as set out in the PCF guide. (Ref 13) The All-Parliamentary Group for Bladder and Bowel Continence Care noted in 2013 that "children seem to be particularly poorly serviced" when compared with deteriorating continence services in general. (Ref 22) From the FOI report above, Scotland compares poorly against the UK as a whole when it comes to service delivery (Ref 21) with a steady decline in indicators since 2014.
- In the same way that services are fragmented with children attending different clinics for different aspects of overlapping problems, the various health care providers involved in children's continence services are also managed and funded by different areas of the health service (and in some areas, the local council.) This creates a situation where the responsibility for funding of staff and equipment is not held by a single chain of command, which means that the costs of essential staffing and equipment are not 'owned' by any one set of managers. This allows for situations to arise where 'no-one is responsible' leading to staff loss, shortages of equipment and lack of accountability and leadership. "Interpretation of roles is causing problems; a funding application for a children's continence nurse was unsuccessful" Lack of meaningful interaction, discussion and planning with clinical staff can stymie efforts to improve services. As one nurse remarked of her manager who announced 're-organisational change' to her job-sharing, 5 day a week, integrated, experienced continence service: "there was no discussion, they'd already made

up their mind; they wanted only 1 person [4 days a week] There was no cover for holidays or sick leave."

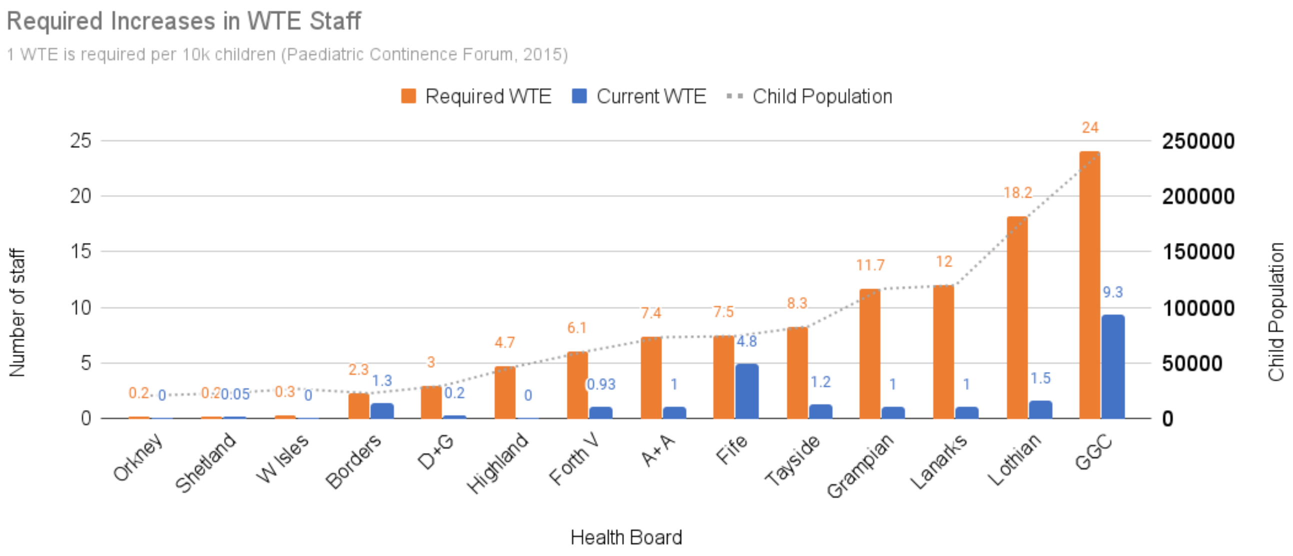
- In another HB, which had received charity funding for nursing staff and equipment to set up a children's continence service, a nurse commented that managers "reneged [on their agreement] to make a part-time post permanent and said that there was nothing in writing" this illustrates the potential for funding to be re-allocated, depending on perceived priorities. In the same HB, 2 continence nurses have not been replaced for reasons of long-term absence and retirement. In one large HB, staff have been attempting to develop a cohesive children's continence service for the past 12 years which has yet to be accomplished. And from one of the largest HBs: "If there was a Specialist [Children's] Continence Nursing team in place then the child and their families would receive a good quality and supportive service"

- Without a designated service that maintains an agreed staff complement, posts may be left un-filled or may be 'lost' or re-allocated elsewhere. In a HB that was without a children's continence service for 7 months due to long-term sick leave and resignation, the reporting nurse said "We have the fundamental processes in place for the service, but unfortunately do not have the resources to practice effectively"

- Charitable funding has been made available by Kidney Kids in response to the lack of allocation of resources by HBs to Children's Continence Services, and in the recognition that bladder and bowel dysfunction is commonly linked to chronic kidney disease. From 2013, they have funded paediatric continence nurses in 3 HBs and provided essential uroflow and bladder scanning equipment. Since 20i6 alone, they have spent £173,491 on continence and urology care to assist Children's Continence Services in Scotland.

1.3 Staffing

1.3.1 General comments



This graph shows the number of WTE staff working in each HB compared with recommended staffing levels (Ref 13) plotted against HB populations (Ref 23). At present, there is a total nationally of 22.2 WTE children's continence nurses compared with the recommended minimum of 1 per 10,000 children (21% of Scotland's population of 5.51 million people are aged 0-18year: National Records of Scotland: 2020 update) which equates to 115 WTE children's continence nurses; **at least 93 nurses are needed to make up this shortfall in workforce.**

- Staffing is a significant problem in all HBs; in 13 of 14 HBs, it limits the ability of existing services to be effective and offer an acceptable standard of service provision with the full range of integrated continence care; "we see so many children that have waited sometimes years in other parts of the health service or who haven't been referred at all coming with gross faecal impaction and overflow soiling; they are in pain and distressed and their families are often at their wit's end over how to help them. They've often been given completely the wrong advice about medication and it's not unusual for them to not be on anything at all or told that they'll 'grow out of their problems'" said one paediatrician

- Only 3 of 14 HBs - NHS GGC, Fife and Borders - report having well-functioning, designated, paediatric continence services with staff numbers approaching the necessary level (Ref 13) for the population they serve; however, they still face barriers to providing an integrated service that addresses all aspects of continence care. None of these services has capacity to specifically support delayed toilet training. In Glasgow, children with daytime wetting attend an entirely separate clinic for this as their continence teams, although well structured, only provide care for children with nocturnal enuresis and constipation. Many children with daytime wetting have related problems with bedwetting and constipation; the model of providing separate clinics for related clinical problems results in more expensive, disjointed care for the child and family, with more time out of school and work to attend multiple appointments. In Fife, despite huge progress with provision of numerous clinics in multiple localities every week, there are still 400 children being seen in more expensive hospital clinics for constipation in addition to those seen within the continence service; this is due to lack of capacity and issues around pathways for children with continence problems. From a Glasgow based nurse: “clinics are crammed full; time is a huge pressure” Most HBs report very large caseloads without adequate staffing levels: a typical comment from one newly reconstituted service which had been without staff for many months due to long term sickness: “this is a massive service and needs more staffing, not counting the large unmet need of children [who have not yet been referred]”

- 3 HB’s have no designated children’s continence service and rely solely on contributions from Community Children’s Nurses (CCNs), Health Visitors (HVs)and School Nurses (SNs). One of these boards has no continence nurse at all for either adults or children, and only has access to a visiting paediatrican once every 3 months; a CCN nurse from this board reports: “services are fragmented- there is no dedicated service” A HV from another board remarked following initiating a project around early years intervention “we have opened the floodgates – where do they go, how do we meet their needs?” All three of these HBs are geographically remote

- Glasgow, Fife and Borders stand out against the remainder in terms of higher levels of staffing; however, neither Glasgow nor Fife services are fully integrated in terms of product provision nor comprehensive, with large numbers of children with either daytime wetting or constipation still being triaged to and seen in secondary care clinics. The recommended WTE staff numbers per 10,000 children is a figure that is currently under review by PCF, and due to demographic shifts and increased numbers of children with disability, will increase in the next iteration of their guidelines (2023)(personal communication)

- The remaining 8 HBs provide a Children’s Continence Service but with a fraction of the necessary staffing complement; they piece together, with variable success, contributions from children’s community nurses (CCN’s), Health Visitors (HV’s) and School Nurses, all of whom fit in this work around other workload commitments. Many reports echo the sentiment of a CCN from a medium sized HB: “dedicated time is needed, allocated to children’s continence service rather than ad hoc; due to other workload this is not currently possible” from a Specialty Doctor in a large HB, again echoed by many, “there is a huge gap in service provision for early years and toilet training”

- Only 2 of 14 HBs have designated children’s continence services that are led by a specialist paediatric continence nurse: it is a key recommendation in the widely accredited commissioning Guide that children’s continence services should be led by a Specialist Paediatric Continence Nurse. (Ref 13)

- Only 1 (smaller) HB has a completely integrated service with the continence nurses assessing and prescribing products in addition to offering the full range of care for all aspects of bladder and bowel dysfunction/continence but is led led by adult-trained nurses

- Services that do exist may cease altogether, or be significantly curtailed, due to staff sickness or retirement; often posts may be 'frozen', left vacant, or re-allocated to another area of need. "re-organisational change [in my HB] means there is no cover for sick leave or holidays"

1.3.2 Health Visitors

- Health Visitors are no longer mandated to advise on toilet training since their role was also 're-focused' (Ref 24). No data is collected or kept on continence milestones or on the increasing numbers of children coming into nursery and Primary one still wearing nappies. Whilst some HV's are knowledgeable about toilet training and continence problems, often they are not from a paediatric nursing background and have little or no specific training in children's bladder and bowel health/ toilet training support within their HV training. *Appendix 3* Many feel unconfident to advise parents and may not be able to pick up 'red flags' "I qualified as a Health visitor in January. I feel inadequate in supporting families with continence issues. I received no training as a trainee HV, and my knowledge is self-taught or from my personal experience" and from a parent: "If I had been given better support and the right information by my Health Visitor, we would have saved years of waiting to be seen by the right person and been given the help that our child needed at the right time"

1.3.3 General Practitioners

- Only 1/4 to 1/3 of GPs are trained in paediatrics; even paediatric trained GPs may not have encountered children with bladder and bowel dysfunction and continence problems during their training, and are often not confident in managing daytime wetting, constipation and nocturnal enuresis beyond the basics

- Myths around the treatment of constipation (laxatives are harmful, extra fibre and fluid intake are first line treatments, medication as a last resort) (Ref 25) means that often children have either not been started on medication for constipation, or have had it reduced or stopped inappropriately, which leads to relapse and chronicity of problems: overflow soiling can then become intractable (Ref 26)

- Overflow soiling resulting from chronic constipation and faecal impaction is frequently misinterpreted, and mismanaged; a continence specialist nurse from a medium sized HB reports a mother of a child with chronic constipation and overflow soiling saying to her when she was finally seen in clinic and receiving disimpaction treatment: "where have you been for the last few years of my child's life?" the nurse commenting further, that "GPs hold on to kids for ages- some great, some not"

- In a HB where there is no dedicated service “GPs contact school nurses on a regular basis for children who have continence problems” but SNs there are limited to giving phone advice according to a nocturnal enuresis pathway only, and cannot address other areas of continence care

1.2.4 School Nurses

- In 5 of 14 HBs currently, School Nurses continue to provide nocturnal enuresis clinics (in the absence of a functioning children’s continence team), but this is increasingly difficult to provide in many areas due to the other specified requirements of their role and a lack of training/support/resources/funding. School Nurses no longer have a mandate to meet children’s physical health needs since their role was ‘re-focused’ in 2013, which resulted in a large gap in provision of enuresis clinics in most HBs as this workforce was not replaced by any other nursing resource. In one HB with no dedicated children’s continence service: a CCN reports that “school nurses only give ad hoc advice according to pathway resources on nocturnal enuresis but don’t hold any clinics” In another larger HB, a manager described school nursing input for nocturnal enuresis as “a ticking time-bomb” and that school nurses “were totally disgruntled” that they had to provide this cover and that it “most likely was no longer in their job plans” but that “they can’t give up on enuresis if no-one else is there to take on the task” In one large HB, half of the localities utilised school nursing for enuresis support, the other half did not, resulting in confusion over referral pathways and clinical responsibilities; recognising the high demand for continence care, one senior nurse from this HB commented: “32% of requests for school nursing assistance were bladder/bowel related” It is important to note that patients are more likely to ask for support for bedwetting than daytime wetting or constipation. This may be because these conditions have not been recognised, or that the stigma and embarrassment associated with them is higher.

- ERIC, the Children’s Bladder and Bowel Charity and Bladder & Bowel UK have produced consensus guidelines and resources for the management of continence issues in a school and college setting. (Ref 27) School nurses are currently unable to accept children onto their caseload however unless their problems fall under one of nine priority areas: physical health needs not being one of these. The only way school nurses can legitimately help with the care of continence problems in school, is to “squeeze them in” under the mental health and well-being pathway, as once nurse put it (Ref 28).

- Children with a range of disability may be accommodated full or part-time in an additional support needs ‘base’ but for those with wetting and/or soiling, there is “no allocated school nurse for children in mainstream ASN bases”

1.3.5 Consultant Paediatricians/Secondary Care Workforce

- Consultant Paediatricians and other secondary care paediatric doctors see a disproportionately large number of children in secondary care clinics due to lack of community-based children’s continence services; this is an expensive and inefficient use of resource. Children may then be discharged after one or two secondary care appointments but have no continuing care or 'step-down' support from lower banded staff - who would be well suited to this role. This often results in relapse, disengagement from services and development of chronic ill-health. One nurse manager commented this results in "regulars recurrently being admitted for disimpaction" and that there were "lots of inappropriate referrals coming in that could be sorted out in the community" Two audits over a span of 3 years in one large HB indicated consistently that between 25 -30% of general paediatric appointments were related to bladder and bowel dysfunction/continence problems. The same HB has a waiting time currently of 6 months for a General Paediatric Clinic appointment. Providing an adequate Children's Continence Service would have clear impact on alleviating pressure on this expensive secondary care resource.

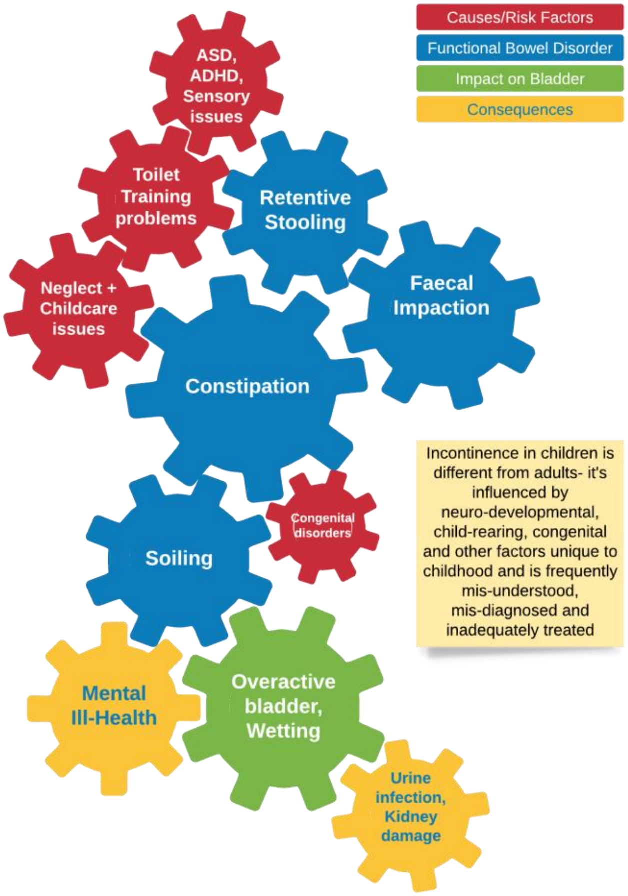
1.3.6 Overall Comment

- School nurses have been able to continue valuable work in some parts of some HBs for nocturnal enuresis but are not able to support continence services in a consistent way. Assuming the presence of a children's continence service because school nurses may be providing care for children with nocturnal enuresis, masks the general shortfall in services in areas where this is the practice. The support of school nurses for children with continence problems in school is important however and currently is not part of the school nursing remit. HV's are well positioned to provide prevention and early intervention at a crucial stage in the pre-school child's life, to reduce the risk of later bladder and bowel dysfunction. Whilst some feel confident in this role and can provide this support, they are subject to many other competing demands due to their re-focused role and have been given neither the mandate nor the resources to deliver prevention and early intervention in continence care. Prior to the revised HV pathway, toilet training was part of the HV remit

- Overall, the understaffed and under-resourced services mean long waiting lists with delays in treatment, an often-disjointed patient journey with restricted access to a full range of treatment, the need to attend multiple different clinics for inter-related problems and adverse outcomes with clinical risk. "Delays are still a problem; pathways are not clear. It needs to be a bigger service from start to finish. More information and education is needed for families." This situation has a significantly negative impact on the child and family as well as being more costly to the NHS.

1.4 Disability, neurodiversity and child protection

- Children with neuro-developmental problems such as autism, ADHD and intellectual disability are more likely to have continence problems than their typically developing peers. These require specific and individually tailored approaches to care. "We see many tricky kids- this takes many appointments, and you can't just lump them together; they have individual issues, distraught parents, [they can be] crying on the phone. Learning disability, ASD, child protection issues- some children are in children's homes and need home visits". These children take more time to assess and manage, need more intensive and prolonged follow-up, and require more multi-disciplinary working alongside education, occupational, speech and language and physiotherapy. Lack of access to a multi-disciplinary team of allied health professionals prolongs their patient journey and increases expense. As one senior nurse manager remarked on the importance of intensive support for children with continence problems "It's the support more than what you prescribe them" Another nurse commented: "I can get assistance for [continence] products with ease, but quite difficult to get additional support for children with additional needs" Additional support is cost-effective: once continent, the child is likely to remain so, and avoid the cost of lifelong product use.



Incontinence in children is different from adults- it's influenced by neuro-developmental, child-rearing, congenital and other factors unique to childhood and is frequently mis-understood, mis-diagnosed and inadequately treated

- Children who have been abused are more likely to develop continence issues, (Ref 29) and children are more likely to be abused if they are incontinent. Child protection scenarios are relatively common in children's continence clinics; this sensitive area requires intensive support for the family and child and requires skilled, time-consuming management and close working with colleagues in education and social services

- 97% of our respondents stated that children with neuro-developmental problems associated with incontinence require extra, skilled support with 99% stating that children's continence services should be multi-disciplinary; however, over ¾ said that services in their HB's were not multi-disciplinary.

- With the scope of continence treatments increasing to include clean intermittent catheterization (CIC), transanal irrigation and care of surgical approaches (Mitrofanoff bladder drainage, ACE procedure) paediatric continence nurses are required to carry out much more complex work with attendant training and support needs for staff, schools and families: "we are doing much more CIC which means more school visits and extra work. Lots of children are coming back from Glasgow now with trans-anal irrigation so we do Peristeen training and support the "Better at Home" team.

- Data collected from one large HB from 2019 showed that there were 1,222 referrals for mental health issues and continence related issues in one year alone *appendix 2*

- Children with spina bifida and neuropathic bladder and bowel, as well as other children with complex congenital conditions such as anorectal malformation, Hirschsprung's Disease and Posterior Urethral Valves require highly skilled management of their continence problems and support within the community; these children are particularly vulnerable during adolescence and need a well-managed transition to bladder and bowel care in adult services

1.5 Training

- Nearly 2/3 of respondents said they did not have sufficient training for their role in supporting children with continence problems. From a HV: "I am so grateful I heard about this course from another HV colleague otherwise I would have missed out on today which would have meant my families continued receiving incorrect advice and substandard support" And from a school nurse who is expected to carry out continence assessments: "I am overwhelmed at times with behaviour related soiling and don't know where to get help from also no idea about assessing for products but expected to do so and never had any formal training at all'

- 100% of respondents said they would like access to further training and refresher courses: "definitely training is required for staff who are front line and managing children with bowel and bladder issues"

- Less than half said they had accessed the Bladder and Bowel health in Children e-Module, which is hosted by TURAS, but also available on the PCS website (Ref 30). The module was commissioned by Scottish Government and developed by the author in consultation with expert colleagues and published in 2020. The intention was for it to be easily accessible for the general public as well as health professionals however this is clearly not the case. From a HV: "I have only accessed the Turas module because of this course"

- There is no provision for post-graduate training in Paediatric Continence as a subspecialty within any Scottish university, which would anchor standards for best clinical practice for specialist nurses and allow cascading of training down through lower banded staff

- Prescribing medication is an essential part of children's continence care and requires supported, additional training for current band 6 and above specialist nurses. This is a relatively scarce skill in the children's continence nursing workforce across Scotland, which necessitates reliance on GPs to prescribe on recommendation of the nurse who has seen the child. Whilst in some areas this system is workable, with quick turnaround of written communications, in others it greatly adds to the difficulty of running an efficient service. Provision of post-graduate courses for non-medical prescribers is limited and places are competitive, making acquisition of these skills more difficult. A nurse specialist related that "GPs may stop or reduce medication inappropriately" and added that: "I can't imagine doing this job without prescribing skills- they are so important" A nurse manager explained that "school nurses [managing enuresis] don't feel knowledgeable or brave enough to recommend medication" even though there are clear pathways that allow this

1.6 Visibility and accessibility of services

- Is poor. Even in those few HBs with relatively well organised services, over half of respondents felt that services were not easily accessible, and nearly 2/3 overall felt that pathways for onward referral were not clear. Remarks repeatedly echoed that "services are fragmented, communication could be better; there should be one point of contact and a dedicated continence service to take the pressure off CCN's" One city centre GP asked with a note of desperation: "can you please just tell me where to send these children?" From an associate Specialist "the clinic is in a single location on one day of the week; travelling by public transport may mean a 1–2-hour journey" Although telephone and virtual appointments are useful and appropriate for many, it remains important for there to be in-person appointments as well to allow direct communication with the child, physical examination and assessment of any potential safe-guarding issues.

- Concerns were repeatedly voiced about the unmet needs of children with continence issues who are not accessing services: "Families often put up with nocturnal enuresis but are struggling and not being referred" This may be due to services not existing, or being poorly developed, but is also due to the stigmatising nature of bladder and bowel dysfunction and continence problems. Children may also not be referred to due misconceptions around what is developmentally normal for age - again this relies on the training of other health care professionals such as GPs and HVs.

- Can be poor for children with disability or chronic health conditions where there are preconceptions of what might be expected in terms of attaining continence. These children may be ‘expected’ to need continence products. Ref1 Diagnostic over-shadowing may result in conditions such as constipation, faecal impaction or urine infections not being considered, even though they are more prevalent in this population. Hence, they may not get treatment that would improve their quality of life, allow them to come out of continence products and become independently continent.

- Pathways are often not clear with inappropriate referrals to the wrong part of the team where there is one: from a specialist urology nurse in a tertiary setting: “100 referrals from GP’s triaged to the [highly specialized] urology nurses uroflow clinic last year and often referral made with no previous continence assessment. There are many other hospital referrals to paediatric surgeons, medical paediatrics, and GI with continence issues and children admitted as inpatients for treatment of constipation” An Associate Specialist commented that there was “no formal platform for discussion, linking with tertiary services” Most children with bladder and bowel dysfunction do not need tertiary referrals or complex investigations however, especially if adequate children’s continence services are in place from the start with early prevention, intervention, and skilled management by qualified paediatric continence workforce.

1.7 Equipment

- Enuresis alarms are a key resource in treating nocturnal enuresis yet often there are difficulties obtaining these in terms of supply lines and budget. A nurse manager explained: “no-one’s paying for these so [school nurses] are not stocking them” From a doctor: “alarms are ordered individually and can take up to 8 weeks to arrive” Many other HBs, including the largest in Scotland, also complained that supplies of alarms were limited. The cost of an alarm - which has up to a 75% success rate in enuresis - is around £50, which is substantially cheaper than the cost of a three-month course of desmopressin in melt form at £180, the alternative first line treatment option.

- Bladder scanning and uroflow equipment are currently only found in specialised secondary care clinics but are relatively inexpensive, automated and easy to use and help facilitate diagnosis and treatment. (Ref 31) Assessing bladder emptying is a key element of practice and should be mandatory equipment for a nurse-led, children’s continence service. (Ref 3) Access to this equipment will reduce unnecessary and expensive referrals to secondary and tertiary care.

1.8 Toilet training

- The emphasis on services being more directed towards the over'5s is a fundamental error and omission, as early problems with bladder and bowel function or disrupted/delayed toilet training are responsible for many children developing costly chronic continence problems with co-morbidities: as one doctor remarked: "Services have been set up for school age children with a huge gap [in services] for pre-school and toilet training" *Appendix 3*

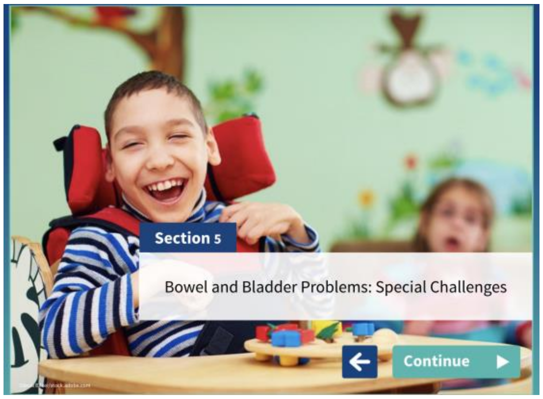
- The YouGov 'Kindred" survey polled 528 teachers in the UK in 2021 who reported that 87% had at least one child in their class who was not toilet trained whilst 9% said that **over half** of the children in their class were not toilet trained, with negative impact on teaching resources and the child's educational experience (Ref 32). Said one senior nurse: "many referrals [to school nurses] come from schools and nurseries as many more children are attending in nappies/pull-ups as they have not been toilet trained (not just children with additional support needs)

- Most HBs with children's continence services do not specifically provide a service for supporting toilet training difficulties in the early years. This is a concern, as over the past 60 years there has been a steady shift in the average age of toilet training from 18 months to 3-4 years of age with many still in nappies on entry to nursery and a significant number still in nappies at school entry. *Appendix 3* There is also a clear correlation with late toilet training and increased risk of bladder and bowel dysfunction (Ref 33) later in childhood, with increased demand on services and use of expensive continence products.

- Many continence problems arise from bladder and bowel dysfunction that starts around the toilet training stage with retentive stooling and constipation common underlying factors. First, these need to be identified as many Health Care Practitioners (HCPs) are unaware of the sign and symptoms. These need to be managed quickly and effectively to limit the risk of progression and persistence of problems. In 6 of 14 HBs there is no support for toilet training.

1.9 Product provision

- The cost of containment products for each HB is not possible to quantify in this report directly from respondents, largely due to the separate working of this part of continence services. However, figures from one large health board extrapolate to a spend of £259,130 p.a. and confirmed figures from a medium sized HB indicate a spend of £103,376 p.a. Scaled up, taking the combined populations of these HBs into consideration, this suggests a total spend on children's continence products in Scotland of £1,450,024 p.a., possibly more. Previous studies by PCF (Ref 3) indicate potential savings of over 50% on product use and spend when a comprehensive paediatric continence service is put in place. Currently, all products in Scotland are supplied by Ontex, who hold figures for all products supplied to under 18's and their cost; a request has been made to them to obtain this information



- New guidelines from a consensus document have just come into place that stipulate that unless there is a rare underlying condition that precludes continence, that every child - including those with disability- should have a full bladder and bowel health assessment and a minimum of 6 months intensive toilet training, supported by an appropriately trained HCP before even being considered for containment products. This support should be offered from the first year of life or as soon as disability is suspected or confirmed. Given the baseline lack of support for toilet training in current services, there does not appear to be sufficient capacity for this in any HB. (Ref 12)

- Most of the nurses who assess and prescribe continence products work in Adult Continence Services, do not work directly with the child and are not paediatric trained. Others are school nurses who may also lack training and expertise in this area: “As school nurses we have almost no more knowledge about products than any other universal community nursing service eg Health Visiting”

- Children in continence products should be reviewed every 6 months with an active treatment plan in place to progress towards achieving continence, if possible, which the majority should be able to. Due to excessive workload and lack of integrated services, children and young people may get ‘stuck’ in products. From available information, only 2 HBs appear to have a regular review system in place carried out by those involved with the care of the child. 4 HB’s may have a review system in place, and 8 did not. “Lots of children are in products, no idea how many, adult trained nurses deal with them, no reviews of products being carried out”

- Children with disabilities are often presumed to need continence products and may not be offered the full range of treatments to encourage them to become continent, which is discriminatory practice.

1.10 Transition points

- With most services for children poorly resourced and some HBs with no dedicated children’s service at all, there is no recognised standard practice in terms of transitioning children on to adult services. A nurse working in the adult continence service in one HB reflected “I still see lots with over-active bladder and constipation at transition (including mainstream and children with disability)” and that “16-18-year-olds are in limbo” Scottish Government has advocated equitable, person-centred and supportive transition processes and specifically states of those with additional support needs that “all young people should get the support they need” Ref (34). The PCF FOI data around children’s continence services in Scotland identified that:

    - only 4 out of 14 HBs offer services for nocturnal enuresis up to age 18
    - only 3 out of 14 HBs see children for daytime wetting up to age 18
    - only 3 out of 14 HBs offer care for constipation up to age 18

  with many only offering services for up to age 16. Adult services may only accept young people from age 18, leaving a gap in service provision. In some areas, children's continence services will only see children up to the age of 10 or 1, for particluar continence problems.

- things can be particularly complex for teenagers with neuropathic bladder and bowel, who face a lifetime of intensive management of their bowel, bladder and kidney health as well as the psychological impact of dealing with long-term continence problems and physical disability. As one teen with Spina Bifida explained: 'I don't mind being a in a wheelchair, I just don't want to be incontinent' However, even people with neuropathic bladder and bowel can become fully continent with the right management and support. This requires a joined-up approach to care that an integrated continence service can provide, rather than colo-rectal nurses, urology nurses and containment product services all offering different aspects of care

- other points of transition which expose the lack of service provision for continence services are between nursery and primary school, and primary and secondary school. HVs may not have carried out the 4-5 year check and may be unaware that a child may be wetting or soiling and still using nappies on school entry. Once in primary school, there is no support given by school nurses for children with continence problems as this is no longer within their re-focused role. Children moving from primary to secondary school with existing continence problems also face a lack of support in the school environment with restricted access to toilets, substandard toilet facilities and staff who have little or no understanding of their difficulties and how to deal with them

1.11 Admin support

- Many services have little or no specific admin support: an Associate Specialist says, “there is no admin support for parent contact and clinic paperwork” Organising and booking clinics, providing a public facing point of contact and dealing with flow of information and paperwork to and from clinicians and families are just some of the essential tasks that admin staff would be required to do. Admin support is cost effective and less expensive than using Band 5,6 or 7 nursing time to attend to these tasks.

- Audit activities flow from carefully managed caseload information and service activities, which is an essential part of good clinical practice and efficient management (Ref 13)

- In some areas, clinics may not be set up on an electronic booking system: “Clinics are not on Trak” This carries potential additional costs due to inefficient use of time. It also makes audit activities more difficult to carry out.

- 5 of the 14 HBs were unable to provide any contact details for any part of a service; one felt they didn’t want to make their contact details public

- different electronic records systems for different parts of the service/ primary and secondary care - not routinely accessed by staff sharing the work of continence services- makes joined up care more difficult: patient records may not be visible on all systems “clinic letter to the GP is entered on Morse but not scanned onto the electronic record”

2 Examples of excellent practice

- Every day, in every Health Board in Scotland, nurses and doctors who care for children with continence problems are giving their very best - often under very difficult circumstances. Despite the intensity of the work, the large caseloads and the frustrations of lack of resources, they say that seeing children become ‘clean and dry’ is the most rewarding thing and will continue their work with dedication and compassion

- One HB has completely integrated care which means a continence products request will trigger toileting skills work with the child and family by the same team

- Toileting support/training programme rolled out to nurseries in a one HB- was highly beneficial resulted in reduced numbers in nappies and more confident, knowledgeable staff

- EYSW/HCSW (Early Years/Health Care Support Workers) are part of the team in some areas- they provide an essential role of support for families and help motivate and encourage adherence to treatment; in some areas they offer early years intervention

- Bladder scanning routinely offered in all nurse-led clinics in two HBs

- Direct input from CAMHS as an integral part of the continence clinics with joint working in one HB

- Nurse-led (non-prescribers) clinics produce care plan /prescribing requests; typed and sent same day, medication available following day

- Close team working with excellent caseload knowledge with good collaboration between different health professionals giving continence care in small HB

- HVs/EYW carrying out structured additional health checks specifically around toilet training and bladder and bowel health at 18m, 27, and 33m

- Structured, reproducible, team working across in all localities across a large HB with clear referral pathways

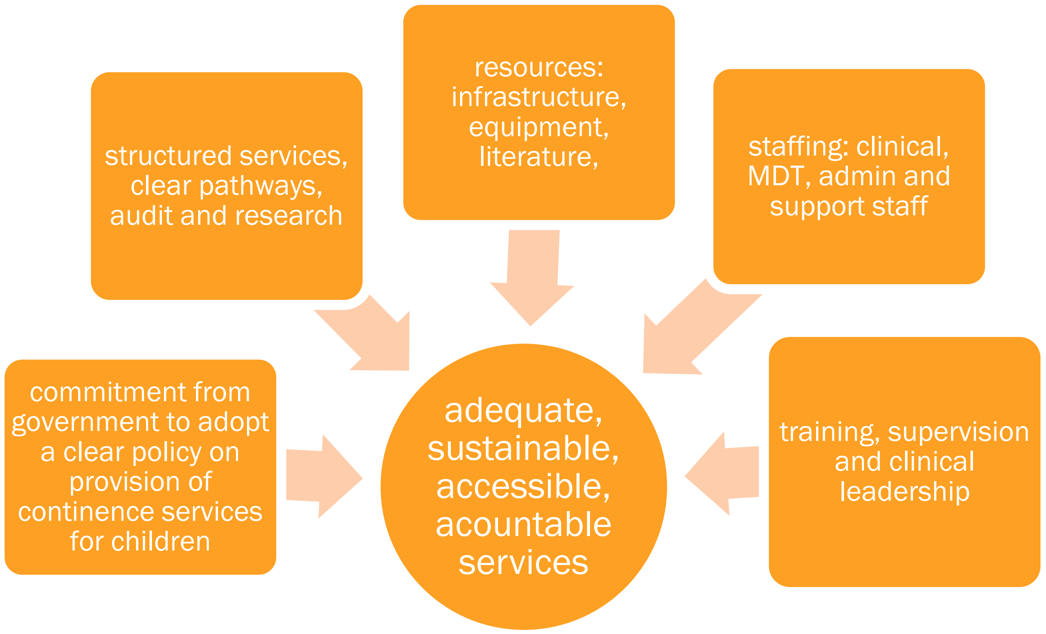
- Nurse-prescriber using rectal scanning, uroflow and bladder scanning to provide a ‘one-stop shop’ specialised bladder and bowel clinic combining assessment and treatment in one appointment

- Use of telephone clinics which have scored over 90% patient satisfaction as measured in one HB; with the caveat that face-to-face appointments at least initially are important to get the child’s perspective, assess child and parent interaction and for examination and bladder scanning if required.

- flexible use of in person, Near Me and phone appointments by many HBs to facilitate patient appointments

- Use of Bladder & Bowel UK and ERIC resources for standardised continence assessments; others using Lothian Guidelines
- One HB senior nurse has tried to make the Bladder and Bowel Health in Children e-Module mandatory for all staff involved with continence care
- GP trainees are taught about children's bladder and bowel dysfunction by the continence team during their attachment
- significant expansion of the children's continence service in one health board over a 4year period to include daytime wetting, nocturnal enuresis, constipation and soiling, diverting much of this caseload away from expensive secondary care and consultant paediatricians

3 What do Scotland’s children need? “The Ask”



- leadership at government level is needed to commit to the set-up of cost-effective, adequately staffed, patient-centered services for children with bladder and bowel dysfunction and continence problems
- consideration should be given to the merits of utilising the Managed Knowledge Network model of service delivery, which allows for creation of Children’s Continence Services in each HB that provide for:
    - equitable services and parity of access to care
    - working to best practice
    - recognised leadership
    - continuing education and training
    - engagement with service users
    - website development
    - audit and accountability

(An application for a Children’s Continence MKN made in 2020, is currently pending.)

- staff quotients should be established for each HBs Children's Continence Service and should be maintained

- every Health Board should ensure they provide a designated, funded, nurse led children's continence service that provides integrated, community-based care and addresses nocturnal enuresis, daytime wetting, constipation, soiling, toilet training support and provision of continence products and works to best practice *appendix 4*

- services should be visible and actively promoted to address the needs of children needing care, accessible within the communities they serve including children up to the age of 18, and include those with disability

- health visitors should be mandated to actively promote best practice around toilet training; they should screen for early onset constipation from birth, carry out structured checks of bladder and bowel health/acquisition of toileting skills from 18 months onwards, and record data on continence milestones

- children's continence services should consist of a multi-disciplinary team with funded support and input from OT and psychology services

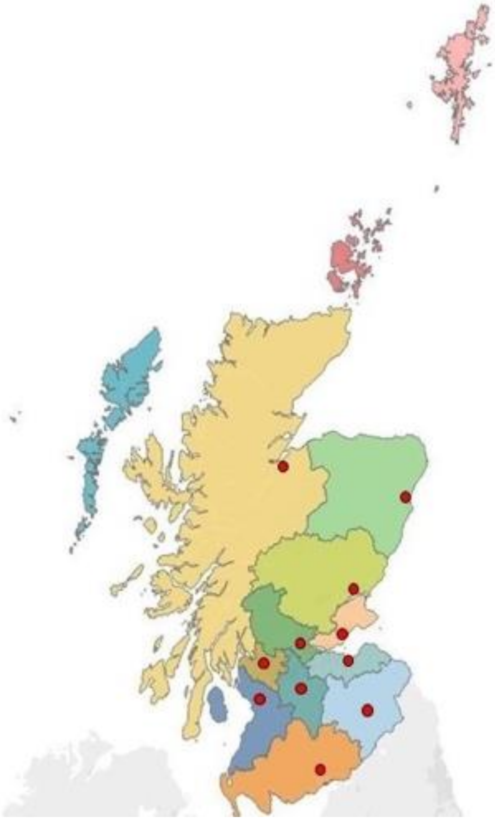
- develop a post-graduate qualification for specialist nurses in paediatric continence

- training should be made available on a regular and frequent basis to enable new and current staff to refresh their knowledge and cascade this to other team members

- teams should be adequately equipped to deliver their service including bladder scanning and uroflow equipment, urine dipsticks, enuresis alarms, laptops, mobile phones and computers

- transition to adult services should be actively managed around the specific needs of the young person

- children's continence services need to provide care from 0-18 and not only offer services from age 5-16 as is currently the case in most HBs in Scotland



4 Outcome Measures

1. Reduced numbers of hospital admissions for dis-impaction/ intensive toileting support
2. Reduced ward admissions for severe constipation/abdominal pain
3. Reduced ward admissions for UTI in context of bladder and bowel dysfunction
4. Reduced A+E admissions for bladder and bowel dysfunction
5. Reduced numbers admitted for uroflow studies
6. Reduced use of, and spend on, continence products
7. Reduced rates of referrals for bladder and bowel dysfunction to consultant led clinics
8. Percentage of children successfully treated within the children's continence service
9. Patient satisfaction – structured questionnaires specific to BBD/QoL

Children's continence services should carry out audit as standard practice to capture this data, with input from Business Units.

Conclusion

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 *Appendix 5* 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.

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.

It is essential to ensure that children with continence problems of all ages, from 0-18, have the best patient journey possible with accessible services and a skilled, trained workforce including multi-disciplinary care. This is in line with "Getting It Right For Children" *Appendix 2.* Putting children's continence services in place across Scotland will improve outcomes for children and their families: good continence care for children will reduce the risk of them developing chronic, long-term continence problems, improve their quality of life, reduce the burden of co-morbidities in physical and mental health, and reduce their vulnerability to harm and discrimination.

This report concludes that creating a national framework for designated, structured, cost-effective children's continence services across Scotland should be a health priority.

Investment in the workforce to provide nurse-led, community-based, children's continence services is an example of spending to save for the NHS, with a financial return in the short to medium term that extends to savings across the lifespan.

Dr. Catriona Morrison
Consultant Paediatrican
Tayside Children's Hospital
Chair, Paediatric Continence Scotland
July 2022

Appendices

Appendix 1

PCS National Service Review: Methodology

- A questionnaire was sent to each of the 14 Health Boards in advance of the PCS Study Day which incorporated the National Service Review; written submissions were returned by 11 of the 14 HB's - the remaining 3 responses were transcribed from telephone interviews with respondents from these HBs, conducted by the author

- Respondents from 10 of the 14 HB's presented their submissions to the National Service review at the Study Day, to an audience of over 180 clinicians involved in children's continence care from all HB's in Scotland excepting Orkney and Shetland. The remaining 4 HBs submissions were presented by the author

- Additional feedback from the Study Day was obtained on several additional questions around accessibility and composition of children's continence services in Scotland, as well as training, for inclusion in this report; a total of 150 individual responses were returned

National Service Delivery Questionnaire, June 2022

PAEDIATRIC CONTINENCE SERVICES IN SCOTLAND JUNE 2022
Thanks for trying to pin down this information from your colleagues in your area! The more accurate it is, the easier it is to give government what they need to develop a plan for providing decent paediatric continence services. Feel free to pop comments in as you go, or at the end!
HEALTH BOARD NAME:
NHS…
Q1. DO YOU HAVE A SINGLE/INTEGRATED SERVICE FOR ALL 4 PAEDIATRIC CONTINENCE ISSUES DISCUSSED ON PAGE TWO? IE. A DESIGNATED PAEDIATRIC CONTINENCE SERVICE FOR DAYTIME WETTING, NOCTURNAL ENURESIS, CONSTIPATION/SOILING AND TOILET TRAINING/ PRODUCT ASSESSMENT AND SUPPLY.
Yes
No

Q2. DO YOU HAVE A PAEDIATRIC CONTINENCE ADVISOR (SPECIALIST NURSE) LEADING YOUR SERVICE?
Yes
No

Q3. IS THERE A MEDICAL LEAD FOR PAEDIATRIC CONTINENCE SERVICES IN YOUR AREA?
Yes
No

Q4. ARE THERE CLEAR PATHWAYS FOR REFERRAL INTO SECONDARY CARE?
Yes
No

Q4. ARE THERE ANY PLANS FOR SERVICE REVIEW IN YOUR AREA?
Yes
No

Q5. PLEASE CAN YOU GIVE A DESCRIPTION OF THE CURRENT SERVICE IN YOUR AREA FOR THE FOLLOWING PAEDIATRIC CONTINENCE ISSUES. AS YOU WRITE THE BOXES WILL GET BIGGER TO FIT!

	Who does this work? Job title, staff numbers, sessions/clinics/days per week or month?	*Where is this service delivered?*	*What works well?*	*What could be better?*
Nocturnal Enuresis				
Daytime wetting				
Constipation/Soiling				
Products/ Toilet Training				

Q6 DO SCHOOL NURSES STILL DO ANY CONTINENCE WORK IN YOUR AREA EG NOCTURNAL ENURESIS?
Yes
No
Q7. WHAT ASSESSMENT TOOLS ARE USED IN ASSESSING FOR PRODUCT PROVISION e.g. LOCALLY DEVISED, ERIC, BBUK?

*Q8. PLEASE PROVIDE ANY FURTHER THOUGHTS OR INFORMATION YOU FEEL IS RELEVANT -INCLUDING **WAITING LIST TIMES** AND **CASELOAD NUMBERS** IF POSSIBLE: WITH THIS INFORMATION WE CAN ILLUSTRATE SHORTFALL IN SERVICES.*

MANY THANKS FOR COMPLETING. PLEASE RETURN TO SUNNI LISTON
sunni.liston@highland.gov.uk

Appendix 2

The SHANARRI Wheel is used to measure 8 essential well-being indicators that are the foundation of "GIRFEC" or Getting it Right for Every Child. This model has been annotated to show how childhood incontinence disrupts well-being in each of these areas. This underscores how important it is to have effective, functioning continence services for children.

Risk of punishment, scolding, belittling and abuse; family tension

Miss out on activities for fear of wetting or soiling accidents

School absences with abdominal pain, UTI's, wetting and soiling; hospital visits

Children may become withdrawn; views and feelings about their condition misunderstood

Chronic ill-health, potentially permanent bladder and bowel damage

Disempowered by lack of bladder and bowel control, unable to fully participate

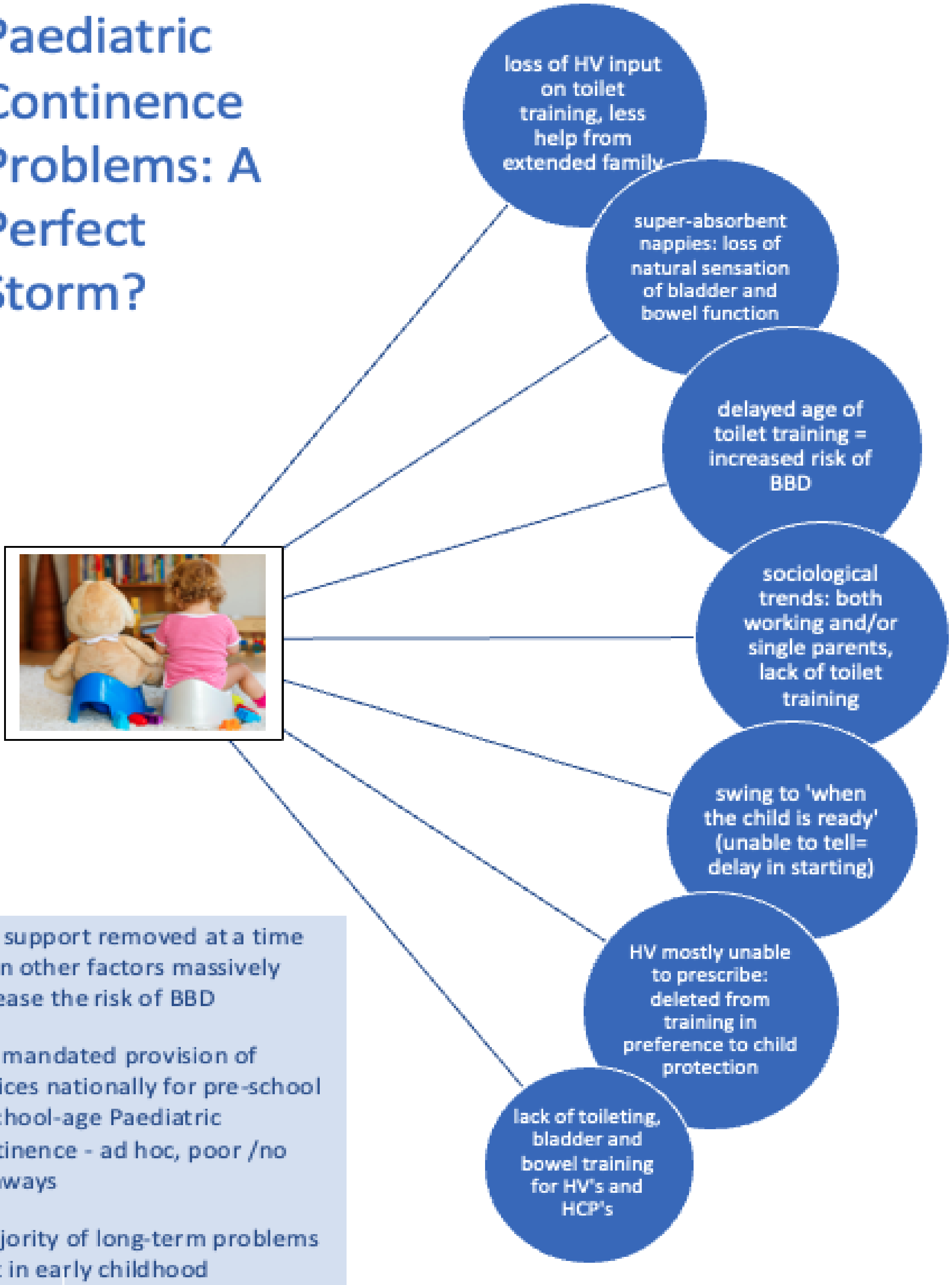
Higher risk of bullying, neglect and abuse

Frequently ostracised and excluded by peers, unable to participate in sleepovers, clubs

Appendix 3

Graphic to illustrate some epidemiological factors for the large rise in bladder and bowel dysfunction, delayed toilet training and the impact of the changing role of HVs.

Paediatric Continence Problems: A Perfect Storm?



loss of HV input on toilet training, less help from extended family

super-absorbent nappies: loss of natural sensation of bladder and bowel function

delayed age of toilet training = increased risk of BBD

sociological trends: both working and/or single parents, lack of toilet training

swing to 'when the child is ready' (unable to tell= delay in starting)

HV mostly unable to prescribe: deleted from training in preference to child protection

lack of toileting, bladder and bowel training for HV's and HCP's

· HV support removed at a time when other factors massively increase the risk of BBD

· No mandated provision of services nationally for pre-school or school-age Paediatric Continence - ad hoc, poor /no pathways

· Majority of long-term problems start in early childhood

· Huge cost to family and NHS, not compliant with GIRFEC and SHANARRI

Appendix 4

Childrens's Continence Services: Structure, Staff, Pathways

Level 4

neuropathic bladder
kidney transplant
bladder surgery
bladder botox
chronic kidney disease

Highly specialised services:
Urologist
Nephrologist

Level 3

"red flag" cases
refractory to treatment
child protection concerns
complex investigations
off-label prescribing
biofeedback

Paediatrician,
Specialty Doctor
Secondary care

Level 2: Paediatric Continence Service

treatment resistant bedwetting
daytime wetting
chronic constipation
faecal impaction/soiling
toilet training with additional support needs
product provision
prescribing and and non-pharma treatment
TENS
trans-anal irrigation
catheterisation
care of surgical bladder and bowel eg ACE, mitrofanoff
training and education
audit
managerial responsibilities
support for level 1 services

Band 7 lead: Specialist Paediatric Continence Nurse: other nursing staff, appropriate skills mix and numbers

Level 1: Paediatric Continence Service

bedwetting and constipation problems should be referred to level 2 after 3 months if no improvement
delayed toilet training: behavioural support, recognise and treat constipation
bedwetting: urotherapy, desmopressin, alarm therapy
constipation: fluids, toileting, macrogol medication
step-down care from level 2 and 3
training and education

Paediatric continence trained nurses/health care assistants, HVs

Pre-service

promote good bladder and bowel health: teach parents what is 'normal'
promote good fluid intake, good toileting habits and good diet
promote and support best practice principles in toilet training
know age-appropriate continence milestones and recognise when these are not met
recognise constipation, treat or refer for treatment
support children with continence problems in schools
aware of and recognise 'red flags'
onward referral to level I or 2 services where needed

HCAs, CCNs, EYSWs,
FNPs, HVs,
School nurses

Appendix 5

Case History: 'Holly' – what can happen in the absence of an effective, integrated continence service

Holly experienced early onset chronic constipation from around the age of weaning, between 6 to 12 months. She passed hard, pellety poos which were sometimes surprisingly big. Small, ineffective amounts of lactulose were given by her GP who told her mum that she would 'grow out of it' and not to give too much medication, in case she 'became dependant on it'. Constipation, painful retentive stooling and overflow soiling made her very late to come out of nappies around age 4. The Health Visitor advised extra orange juice to help with constipation, and reassured mum saying: 'don't worry, she's not going to be going to school in nappies, is she?' However, constipation and soiling continued and soon mum was buying 7 new pairs of pants every week. Mum meantime had been back to the GP to ask for help; Laxido sachets were prescribed, but no instructions were given on how many to take, how to adjust the dose, and how long to take the medication for. Holly continued to soil throughout P1 and 2, then developed problems with daytime wetting and bedwetting as a result of bladder dysfunction, secondary to her faecal impaction which had not been diagnosed or adequately treated by any health professional thus far. By P3 other children bullied and ostracised her; she became socially isolated. She was reluctant to use school toilets and would delay toileting and had little to drink at school, fearing it would make her wetting worse. Children complained she smelt bad. After further visits to the GP, a referral to the adult-led continence service was made. In P4 and 5, she continued to take small, ineffective doses of laxatives on and off, never had disimpaction treatment for faecal impaction, and started wearing the pads prescribed for her by the continence service inside her pants to try to contain wetting and soiling. Both Holly and her mum felt confused and disillusioned, and worried that this was a condition she was going to have for life; they missed several appointments at the continence clinic. Teachers at the school then raised child protection concerns, as Holly had put on lots of weight, was unhappy and withdrawn and they had also been made aware of the missed appointments. A 'Team Around the Child Meeting' was held with Holly's mum. The continence nurse couldn't attend. By this time, Holly was doing everything she could to try to hide her problems with incontinence. She would always stand with her back to the wall. She refused to take part in PE as it would mean changing clothes and worried people would see her pad or soiled, wet clothing. She wore her hoodie tied round her waist if she had to get up to go and fetch something, so people wouldn't see if she'd 'had an accident'. Teachers wondered if she was 'just lazy' and suggested she should 'try harder with her personal hygiene' (verbatim quote). Holly's mum did not understand what Holly's problems were due to or why they were not getting better, and often got angry with Holly out of sheer frustration and her own anxieties over the situation. Holly was discharged from the continence clinic after failing to attend a further appointment. Things did not improve throughout P7 and after Holly transitioned to secondary school, she felt insecure and lost, unable to connect socially and constantly afraid of having humiliating problems with wetting and soiling. In S1, she started to self-harm and expressed suicidal ideation and was referred in to CAMHS via the Crisis Response Team. An astute psychologist, after just one session with Holly where she sensitively took a full history of Holly's problems, correctly identified that the root cause of Holly’s significant mental health problems were the painful experiences around intractable incontinence. She was referred to the specialist paediatric bladder and bowel clinic, where severe faecal impaction was diagnosed and treated. Within 4 months, Holly was almost completely continent for both poo and pee which helped hugely with her confidence and self-esteem, but she continued to have significant problems with mental health and very poor school attendance and peer relationships.

References

Ref 1 https://www.nice.org.uk/guidance/cg99; https://www.nice.org.uk/guidance/qs70

Ref 2 http://i-c-c-s.org/standardisation-documents/

Ref 3 http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf

Ref 4 https://journals.lww.com/ajg/Abstract/2006/10000/Epidemiology_of_Childhood_Constipation__A.32.aspx

Ref 5 http://176.32.230.26/appgcontinence.org.uk/wp-content/uploads/2020/02/excellence-in-continence-care.pdf

Ref 6 https://www.frontiersin.org/articles/10.3389/fped.2020.00084/full

Ref 7 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1820589/

Ref 8 https://www.researchgate.net/publication/44655823_Long-Term_Prognosis_for_Childhood_Constipation_Clinical_Outcomes_in_Adulthood

Ref 9 https://psycnet.apa.org/record/2016-60112-001

Ref 10 https://www.bbuk.org.uk/blog/impact-of-bladder-and-bowel-issues-on-education-for-young-people-in-the-uk/

Ref 11 https://suffolksp.org.uk/assets/SCR-Case-James-091015.pdf

Ref 12 https://www.bbuk.org.uk/wp-content/uploads/2021/06/Guidance-for-the-provision-of-continence-containment-products-to-children-2021.pdf

Ref 13 https://www.bbuk.org.uk/wp-content/uploads/2019/12/PCF-Childrens-Continence-Commissioning-Guide-Dec-2019.pdf

Ref 14 https://www.theyworkforyou.com/sp/?id=2017-11-16.21.0

Ref 15 Ref 9 https://www.sehd.scot.nhs.uk/cmo/CMO(2018)08.pdf

Ref 16 file:///Users/catrionamorrison/Downloads/Rhonda-Reilly-Case-Study%20(1).pdf

Ref 17 http://www.appgcontinence.org.uk/wp-content/uploads/2020/02/CommissioningGuideWEB.pdf

Ref 18 https://www.england.nhs.uk/wp-content/uploads/2018/07/excellence-in-continence-care.pdf

Ref 19 https://www.thelancet.com/journals/langas/article/PIIS2468-1253(19)30297-3/fulltext

Ref 20 https://pedclerk.uchicago.edu/sites/pedclerk.uchicago.edu/files/uploads/Pediatrics-2010-Bongers-e156-62.pdf

Ref 21 http://www.paediatriccontinenceforum.org/wp-content/uploads/2022/06/An-examination-of-paediatric-continence-services-across-the-UK-PCF.pdf

Ref 22 http://www.appgcontinence.org.uk/wp-content/uploads/2020/02/Continence-Care-Services-England-Report-2013.pdf

Ref 23 https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2020

Ref 24 https://www.gov.scot/publications/universal-health-visiting-pathway-scotland-pre-birth-pre-school/

Ref 25 https://adc.bmj.com/content/archdischild/early/2020/03/10/archdischild-2019-318082.full.pdf

Ref 26 https://www.bbuk.org.uk/wp-content/uploads/2017/12/The-Right-Care-Approach-for-Treating-Intractable-Constipation-James.pdf

Ref 27 https://www.eric.org.uk/managing-continence-issues-at-nursery-school-and-college

Ref 28 https://www.gov.scot/publications/realist-evaluation-refocused-school-nurse-role-within-early-adopter-sites-9781788511230/pages/7/

Ref 29 Ref 19 https://learning.nspcc.org.uk/safeguarding-child-protection/continence-issues

Ref 30 https://www.paediatriccontinence.scot.nhs.uk/

Ref 31 https://www.ukcs.uk.net/resources/Documents/15091716_Revised_Min_Standards_for_CC_in_UK.pdf

Ref 32 https://kindredsquared.org.uk/wp-content/uploads/2020/11/Kindred2-YouGov-School-Readiness.pdf

Ref 33 https://www.jpurol.com/article/S1477-5131(09)00356-8/pdf

Ref 34
https://digitalpublications.parliament.scot/ResearchBriefings/Report/2019/3/29/Transitions-of-young-people-with-service-and-care-needs-between-child-and-adult-services-in-Scotland

Abbreviations

ACA	Association of Continence Advisors
ACE	Antegrade Colonic Enema
BAPCUN	British Association of Pediatric Continence and Urology Nurses
CPHVA	Community Practitioners and Health Visitors Association
EYSW	Early years Support Worker
HB	Health Board
HCA	Health Care Assistant
HCSW	Health Care Support worker
HV	Health Visitor
MKN	Managed Knowledge Network
PCF	Paediatric Continence Forum
PCS	Paediatric Continence Scotland
RCN	Royal College of Nursing
RCPCH	Royal College of Paediatrics and Child Health
SN	School Nurse
SPHNA	School and Public Health Nurses Association