MINIMUM STANDARDS for PAEDIATRIC CONTINENCE CARE in the U.K.

for the

UKCS

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PCF

Aims

- Increase awareness of Paediatric continence issues
  - Government / DoH
  - Commissioners
- Improve integration of Community Services

Membership

- Specialist Nurses,
- Paediatricians
- Representatives of:
  - RCN
  - RCPCH
  - CPHVA
- Commercial Members

BACKGROUND: 2014

- UKCS: The Minimum Standards for Continence
  - address ……poor education ….health care professionals

- PCF Freedom of information:
  - < 27% commissioned integrated services

- Paediatric Continence Commissioning Guide
  - NICE accredited

Why is there a need for Minimum Standards for Children?

- The NHS *Improving Quality*
  - “shifting services away from …hospital .. out towards community ….”
- Increasing referrals of children with enuresis and constipation to secondary and tertiary care
  - (Pal et al 2016, Scarlett et al 2015, Thompson et al 2010).

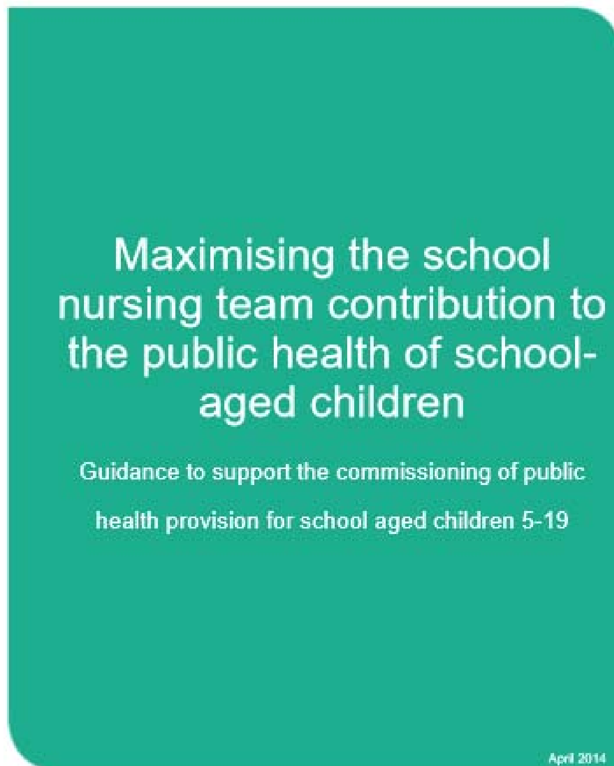
Excellence in Continence Care

- **Treatment for all children and young people**
  - from birth to 19 years old: learning and physical disabilities
- **One community- based service**
  - for children AND young people
  - ***daytime wetting, bedwetting, constipation and soiling***
- **Leadership by a paediatric continence nurse specialist**
  - Input from a multi-disciplinary team
- **Clear and effective referral and care pathways to**:
  - Secondary and tertiary care,
  - Education,
  - Child and Adolescent Mental Health Services (CAMHS)
  - Social services

BUT

- School Nurses and HVs now under LA and PHE control
- LAs and PHE have had budgets cut
- AND….
- "…clinical support for enuresis or incontinence lies with NHS England".
- Continence removed from remit of some school nurses

“Identification of continence issues and referral to appropriate services”



- Prepared by Wendy Nicholson, Professional Officer for School and Community Nursing, Public Health Nursing team, Department of Health

- Identify need on school entry

- Signposting and referral to appropriate providers commissioned by CCGs

January 2016

Public Health England

Protecting and improving the nation's health

Best start in life and beyond: Improving public health outcomes for children, young people and families

Guidance to support the commissioning of the Healthy Child Programme 0-19: Health Visiting and School Nursing services

Commissioning Guide 2: Model specification for 0-19 Healthy Child Programme: Health Visiting and School Nursing Services

- "clinical support for enuresis or incontinence lies with NHS England and clinical commissioning groups"

Two Standards

- **Level 1**:
  - Nursery Nurses, Health Visitors, School Nurses,
    - Commissioned by Local Authorities / Public Health
- **Level 2:**
  - Community paediatric continence nurse specialists
  - some school nurses and health visitors
    - Commissioned by CCGs

Two Roles

- **Level 1: early identification of problems**:
  - bladder, bowel,
  - toilet training problems,
  - including in children with special needs.
- **Level 2: "one community - based service"**
  - children and young people
  - all wetting (daytime and bedwetting),
  - constipation and soiling problems".

Skills: Level 1

- Knowledge of developmental milestones
  - in relation to continence
- Gain a basic history about continence status
  - from child, parents/carers and assess:
- Assess:
  - the impact of symptoms on the child and family
  - their desire for advice.

Skills: Level 1 continued

- Identify when and how to refer
- Provide support and lifestyle advice.
- Promote toilet training,
  - including in children with additional needs.
- Be aware of ‘red flags’

Skills: Level 2

- Take a full history
  - to identify bladder and bowel dysfunction.
- Administer and interpret charts,
  - frequency volume, bowel diaries etc.
- Understand
  - co-morbidities and safeguarding.
- Recognise ‘red flags’.

Skills: Level 2 continued

- Recognise the need to investigate for UTI
  - including urinalysis
- Perform bladder ultrasound scan
- Advise on lifestyle interventions.
- Advise on the use of:
  - enuresis alarms, desmopressin,
  - anticholinergics laxatives.
- Advise about continence containment products.

Skills: Level 2 continued again

- Modify treatment
- Advise on avoiding relapse.
- Provide advice, and training to:
  - Level 1 and other professionals
  - Educational and care staff
- Liaise with
  - GPs, community staff,
  - secondary tertiary care
- Make appropriate onward referrals
  - when treatment outcomes are not achieved
  - ‘red flags’.

Format

- Knowledge base
- Assessment of the patient
- Basic investigations
- Initiating treatment
- Reviewing the outcome of treatment
- Supervision and training

Subheadings

Knowledge criteria	Clinical competence and Professional skills	Training support	Assessment	References
Knowledge of stages of normal physical development including bladder and bowel control and skills related to toilet training	Ability to gain a basic history about continence status from the parents/carers and assess symptom impact and desire for advice.	e-learning, access to appropriate literature	Direct observation	British Association for Early Childhood Education. Healthy Child Programme

References

International Children's Continence Society (ICCS)

Reference	Title	Link
ICCS Clinical tools	1 Week Voiding Diary 24-Hour Frequency/Volume Chart 24-48 Hour Toilet Protocol 72-Hour Frequency/Volume Chart Parental Questionnaire Extended History Taking Bowel Diary Dry Pie Chart	http://i-c-c-s.org/members/Clinical-Tools.cgi

ICCS membership 30 Euros

Comments Please

- UKCS: News and downloads
- http://www.ukcs.uk.net/newsletter-downloads/downloads/policy-documents-downloads/

- PCF: Resources
- http://www.paediatriccontinenceforum.org/resources/

The Community Paediatric Continence Service

- **Effective referral and care pathways to**
  - secondary care
  - education,
  - community mental health (CAMHS)
  - social services
- **Train and support local primary care colleagues**
  - *community nursing, health visitors, GP's*
  - **preventative** treatment
  - **early stage** treatment

PCF PAEDIATRIC CONTINENCE FORUM

The epidemiology of general paediatric outpatients referrals: 1988 and 2006.
Child: Care, Health & Development. 39(1):44-9
E. Thompson, C. Ni Bhrolchain, Wirral University Hospital

	1988	**2006**
Referral Rates per 1000 children per year (<15y)	**15.5**	**25.7**
Most common reasons for referral %	Asthma (15%) Heart murmur (13.8%)	**Constipation (10.5%)** **Enuresis (7%)**

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Most common reasons for referral per 1000 children per year	Asthma 2.3 Heart murmur 2.14	**Constipation** **2.7** **Enuresis** **1.8**

Freedom of Information

Percentage of responders

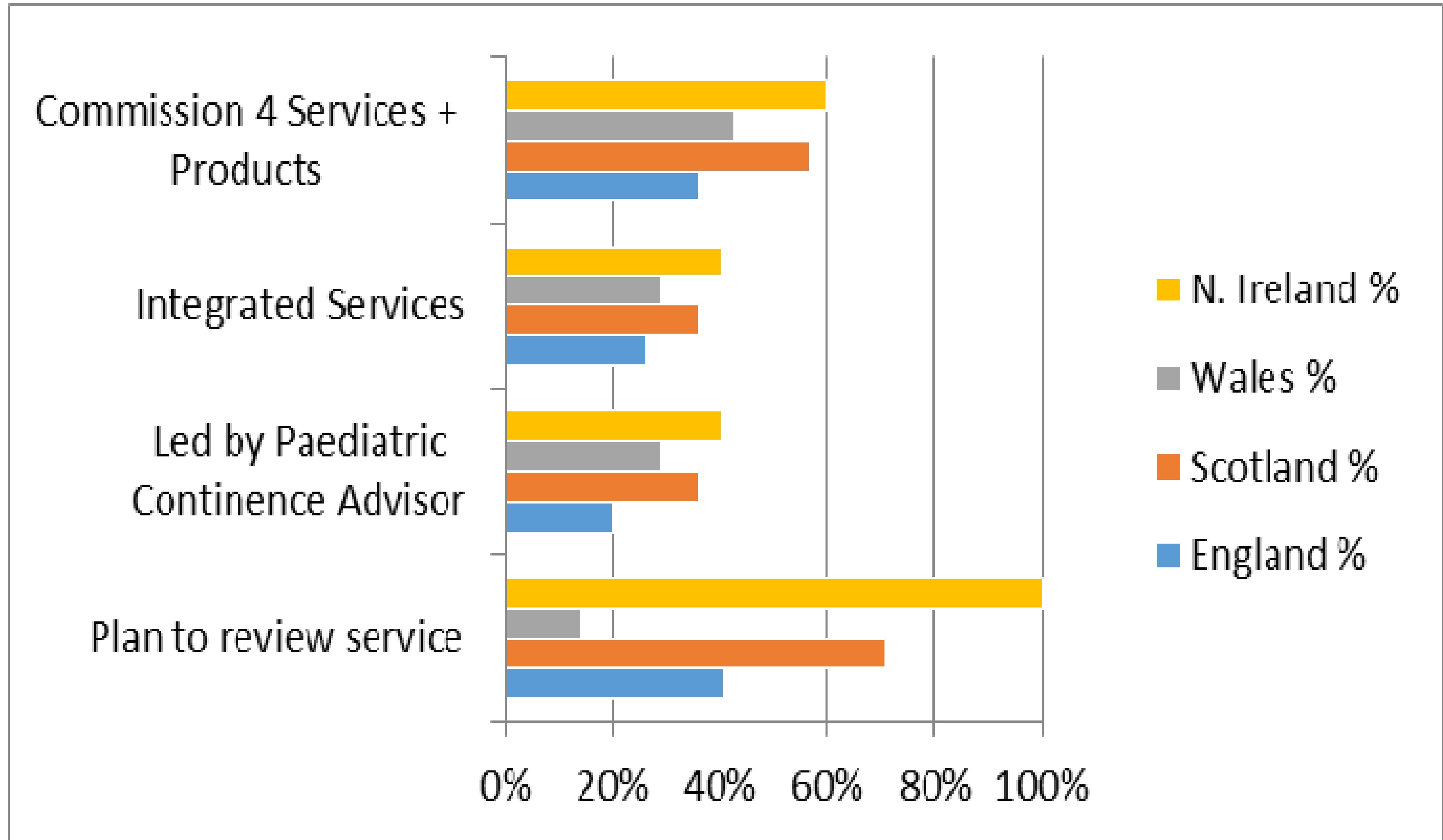
	2011 (PCTs)	2014 (CCGs)
Response rate	47% 72 of 152 PCTs	100% 211 CCGs
% of respondents commissioning all four services	88% (78%-93%)	39% (33%-46%)
% of respondents commissioning a joined-up service	51% (40%-63%)	26% (20%-32%)
% of respondents whose service was led by a specialist paediatric continence advisor	25% (16%-36%)	20% 15%-26%)

Freedom of Information

Percentage of all CCGs

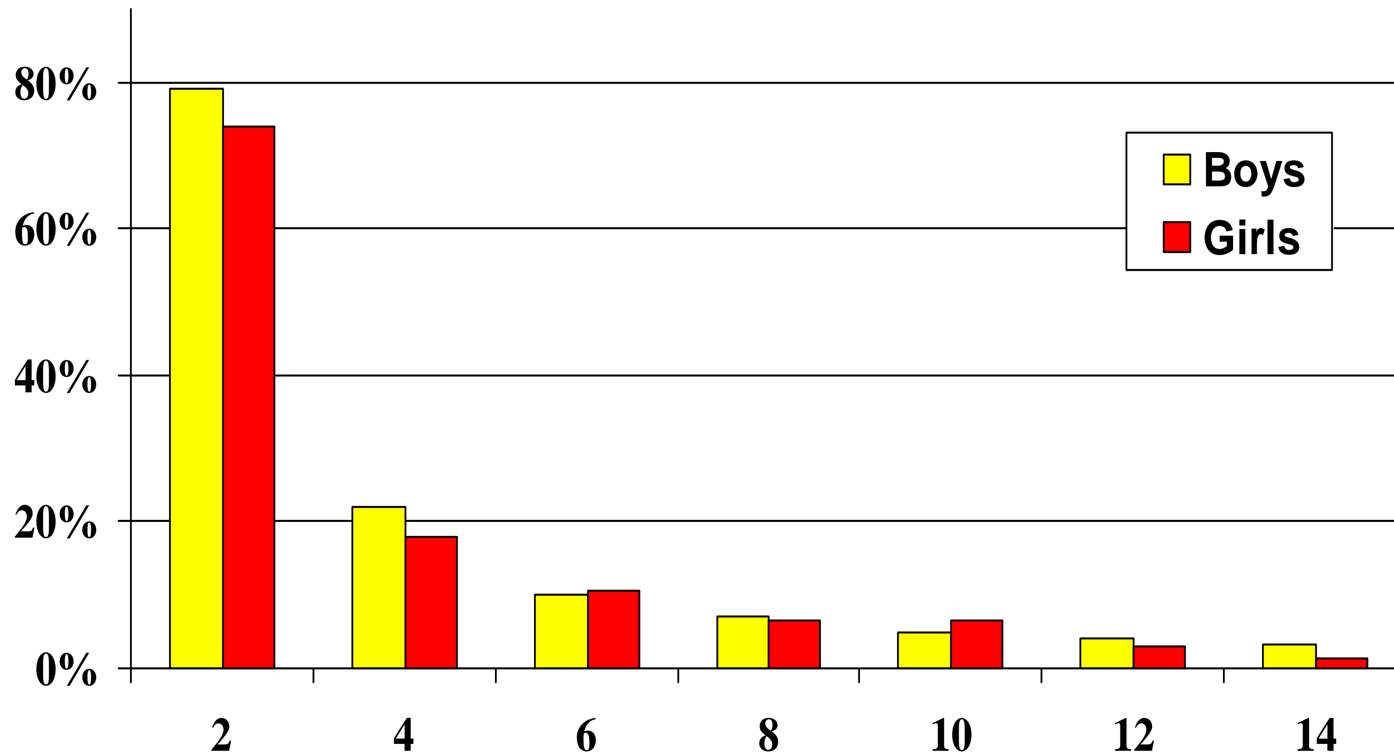
	2011 (PCTs)	2014 (CCGs)
Response rate	47% 72 of 152 PCTs	100% 211 CCGs
% of respondents commissioning all four services	41% (34%-49%)	39% (33%-46%)
% of respondents commissioning a joined-up service	24% (18%-32%)	26% (20%-32%)
% of respondents whose service was led by a specialist paediatric continence advisor	12% (8%-18%)	20% 15%-26%)

Freedom of information: UK

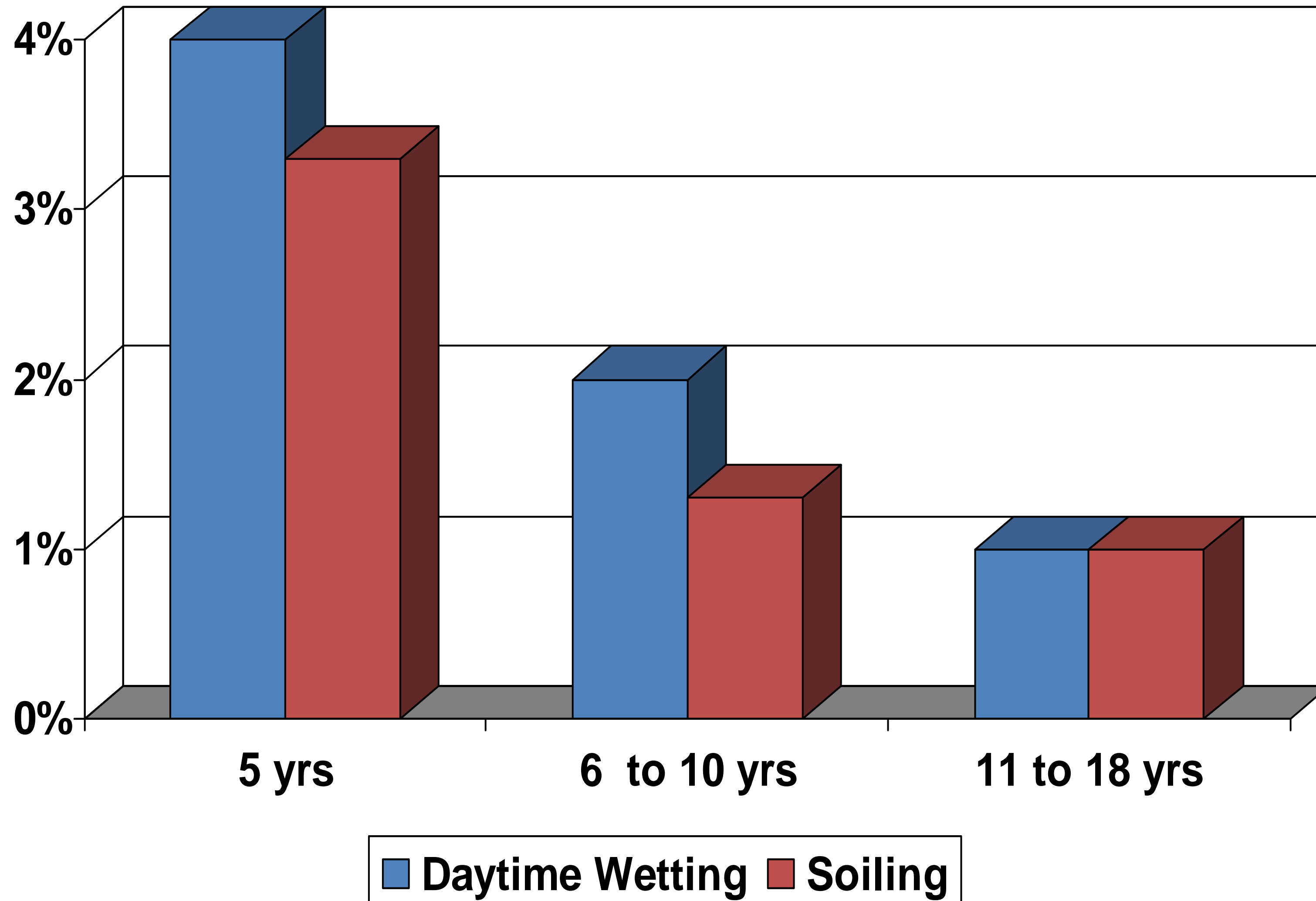


Prevalence of Monosymptomatic Enuresis by Age and Sex

de Jonge 1969, Chiozza et al 1998. DSMIII definition



Incidence of Incontinence in Childhood



ENURESIS: prevalence

Age	**Prevalence %**
5 to 6	21
7 to 9	12
10 to 15	2.3
16 to 19	1.5
20 to 24	2

DAYTIME WETTING: prevalence

Age in Years	Prevalence %
5 to 6	6
7 to 10	3.5
11 to 15	2.9
16 - 18	2
19 - 24	1.5

FAECAL SOILING: prevalence

Age in Years	Prevalence %
4 to 7	4.5
8 to 10	3.5
11 to 16	1.6
16 to 19	1