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

Nicholas Madden
Vice-Chair, Paediatric Continence Forum
Consultant Paediatric Surgeon/Urologist
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
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

“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

<table>
<thead>
<tr>
<th>Knowledge criteria</th>
<th>Clinical competence and Professional skills</th>
<th>Training support</th>
<th>Assessment</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of stages of normal physical development including bladder and bowel control and skills related to toilet training</td>
<td>Ability to gain a basic history about continence status from the parents/carers and assess symptom impact and desire for advice.</td>
<td>e-learning, access to appropriate literature</td>
<td>Direct observation</td>
<td>British Association for Early Childhood Education</td>
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<td></td>
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<td>Healthy Child Programme</td>
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</table>
# International Children’s Continence Society (ICCS)

<table>
<thead>
<tr>
<th>Reference</th>
<th>Title</th>
<th>Link</th>
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<tbody>
<tr>
<td>ICCS Clinical tools</td>
<td>1 Week Voiding Diary</td>
<td></td>
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<tr>
<td></td>
<td>24-Hour Frequency/Volume Chart</td>
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<td>24-48 Hour Toilet Protocol</td>
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<td>72-Hour Frequency/Volume Chart</td>
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<td>Parental Questionnaire</td>
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<td></td>
<td>Extended History Taking</td>
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<td></td>
<td>Bowel Diary</td>
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<td></td>
<td>Dry Pie Chart</td>
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</tbody>
</table>

ICCS membership  30 Euros
Comments Please

• **UKCS: News and downloads**

• **PCF: Resources**
  - [http://www.paediatriccontinenceforum.org/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
Child: Care, Health & Development. 39(1):44-9
E. Thompson, C. Ni Bhrolchain, Wirral University Hospital

<table>
<thead>
<tr>
<th></th>
<th>1988</th>
<th>2006</th>
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<tbody>
<tr>
<td>Referral Rates per 1000 children per year (&lt;15y)</td>
<td>15.5</td>
<td>25.7</td>
</tr>
<tr>
<td>Most common reasons for referral %</td>
<td>Asthma (15%) Heart murmur (13.8%)</td>
<td>Constipation (10.5%) Enuresis (7%)</td>
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<td>Asthma 2.3</td>
<td>Constipation 2.7</td>
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<td>Heart murmur 2.14</td>
<td>Enuresis 1.8</td>
</tr>
</tbody>
</table>

Table showing the referral rates and most common reasons for referral per 1000 children per year in 1988 and 2006.
# Freedom of Information

## Percentage of responders

<table>
<thead>
<tr>
<th>Category</th>
<th>2011 (PCTs)</th>
<th>2014 (CCGs)</th>
</tr>
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<tbody>
<tr>
<td>Response rate</td>
<td>47%</td>
<td>100%</td>
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<tr>
<td></td>
<td>72 of 152 PCTs</td>
<td>211 CCGs</td>
</tr>
<tr>
<td>% of respondents commissioning all four services</td>
<td>88% (78%-93%)</td>
<td>39% (33%-46%)</td>
</tr>
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<td>% of respondents commissioning a joined-up service</td>
<td>51% (40%-63%)</td>
<td>26% (20%-32%)</td>
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<td>% of respondents whose service was led by a specialist paediatric continence advisor</td>
<td>25% (16%-36%)</td>
<td>20% (15%-26%)</td>
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<tr>
<td></td>
<td>(34%-49%)</td>
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<td>24%</td>
<td>26%</td>
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<td>(18%-32%)</td>
<td>(20%-32%)</td>
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<td>12%</td>
<td>20%</td>
</tr>
<tr>
<td></td>
<td>(8%-18%)</td>
<td>15%-26%</td>
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</table>
Freedom of information: UK

- Commission 4 Services + Products
- Integrated Services
- Led by Paediatric Continence Advisor
- Plan to review service

Legend:
- Yellow: N. Ireland %
- Grey: Wales %
- Orange: Scotland %
- Blue: England %
Prevalence of Monosymptomatic Enuresis by Age and Sex

de Jonge 1969, Chiozza et al 1998. DSMIII definition

![Bar graph showing prevalence of monosymptomatic enuresis by age and sex. Boys and girls are represented by yellow and red bars respectively.](image-url)
## ENURESIS: prevalence

<table>
<thead>
<tr>
<th>Age</th>
<th>Prevalence %</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 to 6</td>
<td>21</td>
</tr>
<tr>
<td>7 to 9</td>
<td>12</td>
</tr>
<tr>
<td>10 to 15</td>
<td>2.3</td>
</tr>
<tr>
<td>16 to 19</td>
<td>1.5</td>
</tr>
<tr>
<td>20 to 24</td>
<td>2</td>
</tr>
</tbody>
</table>
## DAYTIME WETTING: prevalence

<table>
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<th>Age in Years</th>
<th>Prevalence %</th>
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<tbody>
<tr>
<td>5 to 6</td>
<td>6</td>
</tr>
<tr>
<td>7 to 10</td>
<td>3.5</td>
</tr>
<tr>
<td>11 to 15</td>
<td>2.9</td>
</tr>
<tr>
<td>16 - 18</td>
<td>2</td>
</tr>
<tr>
<td>19 - 24</td>
<td>1.5</td>
</tr>
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<td>Age in Years</td>
<td>Prevalence %</td>
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<tr>
<td>--------------</td>
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</tr>
<tr>
<td>4 to 7</td>
<td>4.5</td>
</tr>
<tr>
<td>8 to 10</td>
<td>3.5</td>
</tr>
<tr>
<td>11 to 16</td>
<td>1.6</td>
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<tr>
<td>16 to 19</td>
<td>1</td>
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