Why are paediatric continence services an essential service?

Liz Bonner RN DN Cert HV
BSc Hons MSc
Lead Nurse Continence Haringey
Children’s Act 1989
children “in need” to be identified

• Section 17 - local authority services and health to co-operate in the interests of children “in need”. Children with continence problems may be considered “in need” of appropriate management of their continence from Education, Health and Social Services
The Victoria Climbié Inquiry Report
Lord Laming 2003

• Made reference to Victoria lying in her own urine and faeces
• Being “tied up” in a plastic bag full of excrement (Bonner and Wells 2008 Appendix 2)

Children who are abused or neglected are often incontinent of urine or faeces.
Children’s Act 2004

- Places a duty on SHA’s, PCT’s and Foundation Trusts to have a regard of the need to safeguard and promote the welfare of children.
- To ensure that those with chronic and complex conditions such as urinary and bowel incontinence are not ignored.

Maddie Blackburn 2008
Case studies

• 13 year old girl Nisha with spina bifida self catheterises. Lives with 2 older brothers and parents in 2 bedroom flat

• 12 year old Johnny looked after by a series of foster carers since he was 8, bed wetter since age 5. Not always able to access enuretic clinic current area does not have an enuretic clinc. He has just received police caution.
Prevalence

• Prevalence data difficult as few studies and lack of standardisation of types of incontinence

• Children with physical/or learning disability full potential for continence may not be met because of lack of specialised support

<table>
<thead>
<tr>
<th>Children with physical disability (i.e. Cerebral palsy)</th>
<th>50% likely to have a bladder bowel problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with severe learning disability/mental handicap</td>
<td>5 in every 1,000 births, high prevalence of incontinence</td>
</tr>
</tbody>
</table>
## Prevalence

### Bedwetting

<table>
<thead>
<tr>
<th>Age in Years</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>13-19%</td>
<td>19-16%</td>
</tr>
<tr>
<td>7</td>
<td>15-22%</td>
<td>7.5%</td>
</tr>
<tr>
<td>9</td>
<td>9-13%</td>
<td>5-10%</td>
</tr>
<tr>
<td>16</td>
<td>1-2%</td>
<td>1-2%</td>
</tr>
</tbody>
</table>

\[\text{Devlin 1991}\]

### Soiling

<table>
<thead>
<tr>
<th>Age in Years</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>11%</td>
<td>5.2%</td>
</tr>
<tr>
<td>5</td>
<td>3.5%</td>
<td>1.0%</td>
</tr>
<tr>
<td>7</td>
<td>2.4%</td>
<td>0.7%</td>
</tr>
<tr>
<td>10-12</td>
<td>1.2%</td>
<td>0.3%</td>
</tr>
</tbody>
</table>

\[\text{Lukeman 1997}\]
In a class (20 children) of 5 year olds - 4 will be bed wetting, 2 will be wetting during the day and 1 will be soiling
Terminology - Definitions

• Incontinence – means wetting at an inappropriate time and place in a child aged 5 years or older
• Incontinence is subdivided into
  1. Continuous incontinence (associated with malformations or sphincter damage)
  2. Intermittent incontinence
     Daytime incontinence
     Nocturnal incontinence Nevéus (2008)

www.i-c-c-s.org.
Politics and Policy

- **Department of Health** Costs £400 -£500 pounds per year to keep a child/young person in nappies
- **National Service Framework for Children (2004)** long term bladder and bowel problems affect self esteem, full educational potential
- **Disability Living Allowance** - Hidden costs to the family, extra bedding, time for cleaning and changing
- **Local Education Authority** - Schools have to have policies to make sure staff available to toilet and clean children, also to complete intermittent catheterisation
Paediatric Guidelines
Campaigns

- Promoting continence in Children with Disabilities (Bonner 2005)
- Good practice in paediatric continence services
  [www.modern.nhs.uk](http://www.modern.nhs.uk)
- Bog standard
- Water is cool in schools
  [www.eric.org.uk](http://www.eric.org.uk)
Potty training

• Can go wrong
• Disposable nappies do not give wet bottom feeling
• Start to early or to late
• Child will only poo in a nappy
Toilet training - autism

- Children can become very frightened to use the toilet
- Fear of falling
- Splash back onto the bottom
- **Tips** blow bubbles, whistles ping pong balls, washing up liquid
Cognitive dysfunction communication

- Makaton
- PEC symbols
- Picture boards

- Tips - involve school, family and respite
- Reward the good behaviour ignore the bad
<table>
<thead>
<tr>
<th>Go to bathroom</th>
<th>Pull trousers down</th>
<th>Pull underpants down</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sit on toilet</td>
<td>Use toilet paper</td>
<td>Pull underpants up</td>
</tr>
<tr>
<td>Pull trousers up</td>
<td>Flush toilet</td>
<td>Go to sink</td>
</tr>
<tr>
<td>Wash hands</td>
<td>Dry hands</td>
<td>Good</td>
</tr>
</tbody>
</table>
Example of different signs

I pull down my trousers

I pull down my pants

I sit on the toilet

I turn on the taps

I wash my hands

I switch off the light

Back to class
Physical Disability

• Child may need aids and adaptations at home and school
• Teachers and family may need training on how to transfer child without injuring themselves or the child
Constipation/soiling

- Constipation a big problem, poor diet/fluid intake
- Children that soil, often bullied at school and punished by parents
- It can take 12-24 months to treat soiling
Constipation/Soiling

Assessment essential treatment
• Fluids/Diet
• Hygiene
• Toilet training
• Laxatives
• MOTIVATION/SUPPORT to child and family
• Biofeedback
• Anal irrigation
• Surgery - antegrade continence enema, bowel resection, colostomy
Bedwetting – intermittent incontinence whilst asleep

Very common causes a lot of misery and most children will grow out of it.

• Low levels of vasopressin - large wet patch within hours of **going to bed**
• Overactive bladder – dash to toilet more than 8 voids per day, daytime wetting, multiple wetting at night, can wake up after wetting
• **Sleep arousal** problems – sleeps through wetting
LOUD AND SCARY
Managing bedwetting

- Educate parents and child
- Diet/ fluids
- Regular habits
- Charts and stickers
- Treat urinary tract infection
- Treat constipation

- Care for the child with behavioural and emotional problems
- Alarm - body warn or bed
- Medication desmopressin oxybutynin
Neurological – bladder/bowel dysfunction

- Sacral agenesis
- Spina bifida
- Spina bifida occulta
- Hirschsprungs Disease
- Spinal injury

- Not all conditions diagnosed at birth
- Child may have bladder/bowel problems for years before diagnosis
- Child at risk if late diagnosis renal dysfunction, mega colon
Neurological bladder assessment/treatment

• Urinalysis - mid stream
• Post void residual
• Charting
• Full diet/fluid history
• Family history
• Developmental history
• Physical – height, weight, blood pressure, neurological, genitalia

• Urgency regular toileting,
• increase fluids Anti cholinergic medication
• Recurrent UTI - investigations Prophylactic antibiotic therapy
• dysfunctional voiding biofeedback
• Incomplete emptying – intermittent self catheterisation
investigations

Refer for further investigations if –

• abnormal voiding pattern indicating obstruction
• incomplete bladder emptying
• persistent dribbling risk of renal failure

Need to be aware of risk
• Sexually transmitted disease
Transition – long term bladder bowel management

- Children with incurable bladder or bowel problems require access to specialist paediatric continence services. Their family teachers and carers require training and support.

There are many problems to avoid and overcome.
- Skin care, odour, urinary tract infections, renal damage
- Exclusion from education and school trips
- Dependence on carers to go into school to change soiled child, affects family finances
- Bullying – Isolation
- Child protection – always be aware of risk of many carers changing products or performing intermittent catheterisation, enemas suppositories and anal irrigation
Essential checks for paediatric continence services - benchmarking

- Information for children and families
- Access to professional advice re continence bladder and bowel care
- Assessment of individual patient
- Regular evaluation of care
- Education for professional assessors and care planners
- Health promotion bog standard water is cool
- Access to continence supplies
- Education of the carers
- Equipment and environment to meet child’s needs
- Child and family support groups
- Parent and child involved in designing services
Why are paediatric continence services an essential service?
Bibliography

