SOLIHULL ENURESIS SERVICE REVIEW
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Background

**Enuresis** = ‘intermittent urinary incontinence at night-time’ in a child otherwise expected to be dry.

Enuresis = Nocturnal Enuresis = Bedwetting

Enuresis often leads to severe psychological disturbance in children, and limits their ability to learn and interact.

NICE advocate dedicated community services for paediatric continence, yet few areas tend to operate such services nationally. Solihull offers a community service for enuresis led by school-nurses.
Enuresis: 3 Biological Causes

Disambiguation:
Enuresis is usually a cause of psychological disturbance in children, and not a result of it.
Enuresis: Management

**Management:**

- **Devices** (alarms)
- **Drugs** (desmopressin, tricyclics).

The enuresis service specialises in advice and 1\textsuperscript{st} line management.

2\textsuperscript{nd} line management is reserved for outpatient secondary care.
Drivers for review

Local:
• Tendering of school nursing services
• Increased waiting times – need to review resources
• Stretched financial resources – need to prove efficacy
• No recent review available

National:
• Childhood continence care generally under-resourced and under-regulated (NICE)
• NICE guidance on management of enuresis available to define best practice
**Review Framework**

The well-established *Donabedian (1966)* framework of ‘structures’, ‘processes’ and ‘outcomes’ was used to categorise review areas:

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Review Timeframe

October 2013 – August 2014
Results: Structures

Staffing:

Average allocated clinical hours: 0.32 WTE/ year
Average allocated admin hours: 0.07 WTE/ year

However, due to recent staffing shortages, the average clinical and admin hours are likely less than allocated.

Recommendations:
1. The Paediatric Continence Forum (2014) recommend 1 WTE clinical hours per 100,000 resident population. However, this would be for a bladder and bowel care service, whereas the enuresis service specialises in bladder care only. Therefore, it may be reasonable to staff 1 WTE clinical hours per 200,000 population for an enuresis service, although no clear target is available. (Solihull population approx. 200,000)
2. Also, the PCF recommend a community paediatrician is designated as a source of support or guidance to the service as needed.
Results: Structures

Access:

Figure 1. Funnel plot showing referral rates by registered GP practice
(Oct 2010-2013 aggregate data on referrals)

The funnel plot above shows the distribution of referral rates around the mean by registered GP practice of patient (each point is a specific Solihull GP practice). The red lines represent control limits (at 3 standard errors from mean) which allow for chance related variation in referral rates. Points falling outside this ‘red funnel’ demonstrate unusual activity. All except one practice are within control limits. One practice is displaying unusually high referral rates. Referrals from this practice should be monitored for appropriateness if this unusually high referral rate persists – details available from review author.
Results: Structures

Equipment:

The following products were listed within 2011-13 invoices:

- Malem MO4 Alarms
- Malem Easy Clip Sensors
- Malem Flat Plate Sensors

All products are registered with the US FDA on their medical device database and CE marked.

Equipment satisfactory
Results: Structures

Training:

- A 2 day training course is provided by ERIC for new clinical staff
- A training induction pack is issued to all new clinical staff
- A period of mutually agreed supervision is provided for all new clinical staff

Training pack covers key skills generic to children’s services. However, I recommend that a copy of the latest NICE pathways for the assessment and management of enuresis are included in this training pack.

Recommendation: Update training pack with latest NICE guidance.
Results: Structures

Confidentiality:

System One is used to record patient identifiable data onto secure servers in primary care facilities.

In 2013, 27 patients completed the Children’s and Young People’s Services Questionnaire (CYPSQ) which is a generic patient satisfaction questionnaire given to patients/parents after their first appointment at the enuresis clinic.

2/27 respondents to the CYPSQ disagreed that they were told about confidentiality in their appointment.

Recommendation: Confidentiality is well protected in the clinic. Staff should ensure that patients are made aware of the confidential nature of the service at all first appointments.
Results: Structures

Stakeholder Involvement:

No documented evidence of recent stakeholder involvement found.

**Recommendation:** Ensure there is a system in place for stakeholder involvement in service delivery: this should include patients, clinic staff, schools and wider healthcare services.
Results: Structures

Safeguarding:

Up-to-date safeguarding training courses (level 3) are incorporated into the training structure for all school nurses as a requirement by HEFT. A clear local safeguarding protocol is available to all school nurses.

Safeguarding satisfactory
Results: Processes

Integration (with wider healthcare/non healthcare sectors):

The service demonstrates broad visibility across health and education sectors and parents/families. Satisfactory
Results: Processes

Clinic activity + Waiting times:

Referral Activity (2011-13)

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of new referrals made</th>
<th>Number of new referrals seen</th>
<th>Number of follow-ups seen</th>
<th>Number of inappropriate referrals</th>
<th>Proportion of appropriate referrals seen</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>187</td>
<td>192</td>
<td>290</td>
<td>2</td>
<td>1.04</td>
</tr>
<tr>
<td>2012</td>
<td>183</td>
<td>110</td>
<td>195</td>
<td>3</td>
<td>0.61</td>
</tr>
<tr>
<td>2013</td>
<td>165</td>
<td>122</td>
<td>196</td>
<td>0</td>
<td>0.74</td>
</tr>
</tbody>
</table>

Average waiting times have exceeded 18 weeks repeatedly over the last 3 years. Fewer referrals are being seen in 2012 +2013 compared to 2011.

Recommendation: increase staffing to 1 WTE clinical hours to manage demand. Monitor DNAs which may account for some reduction in referrals seen.
Results: Processes

Referral Processes:

There are 2 criteria listed for entry referral in the local Solihull ‘Enuresis Pathway’ document:

- Child must be aged 5-18
- Child must reside in Solihull borough, attend a Solihull school or be registered at a Solihull based GP.

Specific clinical criteria are not listed and there was no pathway identified for referral out of the enuresis clinic onto secondary care services.

Results: Processes

Assessment/Management:

Assessment and management pathways were identified in the local Solihull ‘Enuresis Pathway’ document:

This pathway does not demonstrate full use of the NICE guidance on the assessment and management of children with enuresis. No/limited information is provided on:

• history taking and assessment,
• deciding between treatment options
• follow up protocols for desmopressin

Results: Processes

Promotion/Prevention:

There was no evidence of planned promotion/preventive activity with regards to enuresis.

Recommendation: Introduce some planned promotion/prevention activity for enuresis. This could include a seminar with health visitors for example, who may be in an ideal position to pass on early continence advice to local parents.
Results: Processes

Audit processes:

No regular audit/review processes currently in place.

**Recommendation:** Introduce a protocol for regular planned audit of performance. This review can provide a template for any future work.
Results: Processes

Infection Control:

All children receiving alarm treatment are given a new sensor in compliance with NICE guidance as observed directly in clinic and as discussed with the clinical lead nurse for enuresis.

Infection control is also listed as a key learning objective in the new starter training pack.

However, 5/24 respondents to the CYPSQ (for year 2013) disagreed that staff washed their hands during consultation.

Recommendation: Staff should attempt to wash hands visibly in the presence of patients. However, infection control procedures are generally well established.
Clinical Effectiveness: short term outcomes

Follow up patients seen **June – Aug 2014** were sampled for short term dryness. This was defined as a minimum period of 14 consecutive dry nights since starting treatment at the clinic. This indicator is recommended as a key outcome measure by NICE in the management of enuresis. Targets were identified from COCHRANE systematic reviews on the efficacy of treatments.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>n</th>
<th>Proportion dry 14 nights [95% C.I.]</th>
<th>TARGET</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alarm</td>
<td>13</td>
<td>0.77 [0.46 - 0.95]</td>
<td>0.67</td>
</tr>
<tr>
<td>Desmopressin</td>
<td>12</td>
<td>0.75 [0.43 - 0.95]</td>
<td>0.19</td>
</tr>
<tr>
<td>Advice only</td>
<td>15</td>
<td>0.33 [0.12 - 0.62]</td>
<td></td>
</tr>
</tbody>
</table>

The service is demonstrating **excellent** short term clinical outcomes, beating targets. The average duration of treatment was approximately 3 months at follow up for both alarm and desmopressin. (Without treatment, only 4% of patients would be likely to resolve spontaneously in 3 months).
Results: Outcomes

Clinical Effectiveness: long term outcomes

Data was also collected on long term outcomes. NICE recommend reviewing dryness at 6 months post discharge, to assess for 6 consecutive months dryness. During June/August 2014, 50 questionnaires were posted to patients discharged 6 months or more in the past (activity conducted by HEFT patient engagement services to protect patient confidentiality)

Currently, there are only 4 responses of which 2 patients remain dry, and 2 patients have improved but not fully resolved symptoms. Patients not fully dry will be sent advice on how to contact the clinic for further support.

Recommendation: Note that 50% recurrence rates at 6 months can be expected even with the achievement of short term dryness (COCHRANE evidence) and we must await further responses or seek greater sample sizes to comment on performance against long term dryness.
Results: Outcomes

Clinical Effectiveness: quality of life

Baseline QoL scores were collected from 17 new patients (June – Aug 2014) competing the validated PinQ quality of life questionnaire for children with continence problems.

The average response score was 25.5 with a standard deviation of 14.0, reflecting baseline scores and standard deviations found in the wider literature, and establishing that enuresis is a significant cause of psychological disturbance in children attending the clinic.

PinQ themes in sampled children

<table>
<thead>
<tr>
<th>Greatest Concerns</th>
<th>Least Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;I would feel better about myself if I didn’t have a bladder problem&quot;</td>
<td>&quot;I think about my bladder problem when choosing which sport to play&quot;</td>
</tr>
<tr>
<td>&quot;If my bladder problem was fixed I would invite more friends into my house&quot;</td>
<td>&quot;I choose hobbies that won’t be spoiled by stopping to go to the toilet&quot;</td>
</tr>
<tr>
<td>&quot;I miss out on doing things because of my bladder problem&quot;</td>
<td>&quot;People in my family treat me in a different way because of my bladder problem&quot;</td>
</tr>
</tbody>
</table>

Follow up QoL were requested at 6 months post discharge (as for long term dryness) with only 4 respondents. Those dry had QoL scores of 3 and 5 and those still wet had scores of 29 and 38.

Recommendation: await further responses or increase sample size.
Results: Outcomes

Patient Satisfaction:

The CYPSQ was completed by 27 responders in 2013. 4 domains of patient satisfaction were identified with regards to the care received during clinic. The clinic performs very well against all domains, with almost 100% of patients reporting high levels of satisfaction with the care received.
Solihull experiences a north/south divide in terms of deprivation. Often, people from deprived areas have reduced access to healthcare services. The Solis (north) and Sirius (south) groups categorise Solihull GPs into north and south zones. Enuresis is largely biological in nature, and there is no robust evidence to support increased prevalence in socio-economically deprived groups.

Referrals by GP registration zone (north vs. south) are representative of the regional populations for under 18s. This suggests that deprived areas have good access to the enuresis service.

**Recommendation:** look for equity in clinical outcomes. Monitor characteristics of DNAs – are children referred from deprived areas failing to attend appointments?
Results: Outcomes

Staff Satisfaction:

Concerns were raised regarding the insufficient staffing (both clinical and administrative) of the service, and the impact this was having on staff workload and stress.

Otherwise, positive attitudes were expressed with regards to the importance and quality of the service offered. Staff gain satisfaction from successfully treating and improving the lives of local children, and value the service.

Recommendation: Increase staffing and manage staff workload to reduce stress and improve working conditions and staff satisfaction. Involve staff in the management and decision making processes related to the clinic conducted by HEFT.
Results: Outcomes

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Results: Outcomes

Complaints/Adverse Events:

Patients/parents responding to the CYPSQ expressed concerns regarding the lengthy waiting times, although they were very happy with the quality of the service received once an appointment was made available.

No adverse events with regards to patient safety were identified. However, a recent temporary closure of the enuresis waiting list was deemed necessary due to staffing crisis and excessive waiting times.

Recommendation: Increase staffing to reduce waiting times within normal limits (less than 8 weeks) – this has rarely been achieved in the last 3 years. Increased resources will reduce the risk of future list closure, loss of confidence in service, and improve user satisfaction.
Results: Outcomes

Costs vs. Savings:

<table>
<thead>
<tr>
<th>Principals 'Costs'</th>
<th>Principal 'Savings'</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Staffing</td>
<td>Outpatient activity: new patient</td>
</tr>
<tr>
<td>Administrative Staffing</td>
<td>Outpatient activity: follow up</td>
</tr>
<tr>
<td>Clinic Overhead Costs</td>
<td></td>
</tr>
<tr>
<td>Staff Training Costs</td>
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</table>

The enuresis clinic has demonstrated excellent short term clinical outcomes. The costs of running the service is approximately £41,500/year, and the service provides relief for local paediatric outpatient services (as the use of desmopressin and alarm treatments is generally outside the scope of primary care in Solihull). If the service were removed, and the assumption made that outpatient services would manage the yearly demand for enuresis care, the costs to the healthcare system would almost double. Therefore, the clinic is working at a saving of £35,329 to the healthcare system.

Recommendation: continue to fund service which provides good clinical outcomes for less expense than outpatient model. (Note that the figure of £37,241 for staffing assumes a staffing increase to 1 WTE clinical hours as recommended earlier).
Summary of Recommendations

Structures:

- Increase staffing
- Involve stakeholders
Summary of Recommendations

Processes:

- Strengthen documentation of referral pathways
- Strengthen documentation of assessment/management pathways
- Ensure regular audit
- Offer regular health promotion/prevention activity
- Ensure hands washed visibly with each patient contact
- Reassure all patients about confidentiality
- Aim for higher response rates to CYPSQ – ask patients to complete while waiting for their first follow up appointment
- Audit non attenders to ensure equity in access
Summary of Recommendations

Outcomes:

- **Conduct a larger audit of long term outcomes**: dryness at 6 months and quality of life at 6 months
- **Monitor equity in outcomes**: are patients from north less likely to comply with/respond to treatment?
- Providers to monitor staff satisfaction and involve as necessary
Any Questions

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Key References

National Institute for Health and Care Excellence (NICE), (2014). *Commissioning a paediatric continence service.*


Paediatric Continence Forum (PCF), (2014). *Paediatric Continence Commissioning Guide*

National Institute for Health and Care Excellence (NICE), (2010). *Costing Statement: Nocturnal Enuresis*


