

Children's Continence Service – An Affordable Luxury?

RCN advisor Amanda Cheesley (2012) in a statement about cuts and lack of development of specialist nursing posts stated;

“ they (specialist nurses) are wrongly perceived to be an expensive luxury. It is not understood that they bring cost savings, benefits to patients and vital support for other nurses, medics and multi disciplinary team.”

It could be argued that the children's continence service, offering nurse led continence care, is a luxury service. Therefore this study seeks to examine the cost of providing this community nurse led service and the outcomes achieved in comparison with a similar service provided in secondary care led by paediatric consultants utilising a cost effectiveness analysis.

The study was a collaborative project between The Royal College of Nursing and the Office for Public Management, funded by the Burdett Trust for Nursing.

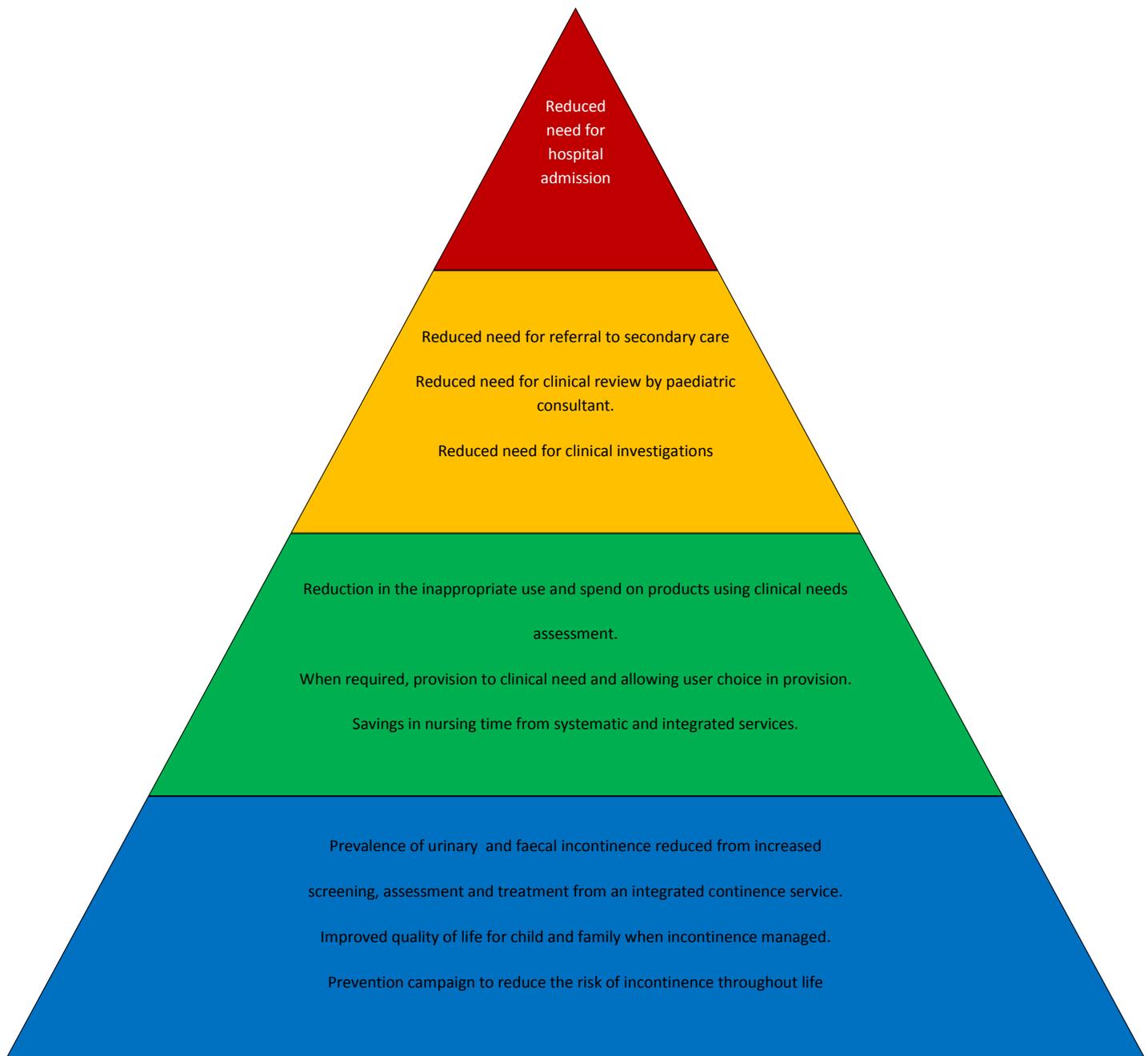
The need for integrated children's continence services was first highlighted in Good Practice in Continence Services (Department of Health 2000); and in 2004 the children's National service framework recommended that ' an integrated community based paediatric continence service, informed by Good Practice in Paediatric Continence Services, ensures that accessible, high quality assessment and treatment is provided to children and their parents.'

The All Party Parliamentary Group for Continence Care Report (2013) highlights a significant decline in the level of provision of continence care services, poor outcomes for patients and soaring costs to the NHS. It found continence care costs have increased from £77million in 2006/2007 to £121million in 2010/2011. The survey reported that while continence services have experienced an increase in patients, few reported an increase in budget or staff; children and young people continence services were found to be particularly affected.

NICE guidelines (2010) for management of childhood constipation and management of childhood nocturnal enuresis (bed wetting) advocate community based continence clinic and highlight possible benefits of the service to include

- **greater awareness of continence problems resulting in improved identification**, early intervention and faster referral-to-treatment times
- **reducing costs resulting from inappropriate referrals to paediatricians** and preventing unplanned hospital admissions for children and young people with abdominal pain caused by chronic constipation
- **improving clinical outcomes and quality of life for children and young people and their families** through evidence-based treatment that promotes continence, preventing unnecessary long-term reliance on nappies and pads and the need for surgery
- **increasing clinical and cost effectiveness**: by making commissioning decisions based on NICE guidance and accredited information from NHS Evidence, commissioners can ensure that they are using their resources more effectively.

The Prevention Pyramid demonstrates the risks and rising costs of untreated incontinence, and how an effective integrated continence service can reduce the risks and therefore costs.



Source: Framework for Economic and Cost Evaluation for Continence Conditions (2006). Report by University of New South Wales. www.toiletmap.gov.au

Children's Continence Service Overview

The nurse led children's continence service was set up in 2010 in the community. It is fully funded by the Western Health and Social Care Trust and the budget for the service is held within the children's community nursing team budget. It is a substantive service provided by staff on permanent contracts; it is staffed by two full time band 6 registered nurses, covering two geographical areas.

The service works with children and their families, as well as education and voluntary groups, providing continence related education and careplans when required. The service operates an open referral system and is available to all children in the Trust area aged 0-18yrs.

For the purposes of this economic analysis, only the data from one sector of the Trust – the Northern sector was considered, as it was not possible to collate the data from the Southern sector within the time frame. However it is assumed that there is no significant difference in the data from the two sectors and the conclusions drawn are applicable in both sectors.

Children's Continence Service – Pathway to Outcomes

Input

Direct

- 1 WTE Band 6 nurse
- Secretary Band 2- 8 hrs/wk
- Service funded from CCN budget
- Clinical rooms within Trust properties
- Clinical supplies and equipment – enuretic alarm, urine testing strips, bladder scanner, uroflow
- Office supplies and equipment
- Nurse training/skills update-continence course

Indirect

- Travel costs
- Download information leaflets from ERIC, promocon
- Leaflets from pharmaceutical companies
- Non medical prescribing
- Containment products
- Training in schools, charities

Activities & outputs

- Clinics/home visits/telephone
- assessment
- investigations – ultrasound scanning, uroflow, urinalysis
- diagnosis
- individual treatment/management plan
- follow up and review
- independent nurse prescribing and continence medication review
- referral on
- discharge
- education of carers / health care professionals, education professionals, voluntary groups
- multidisciplinary working health and education

Groups targeted

For intervention

- Children aged 0-18yrs who have a continence issue residing in the Northern sector of the Western Trust

For partnership

- Children with continence issues
- Carers of children with continence issues
- Other health professionals involved with children with continence issues
- Education professionals
- Support groups eg. ASD, Downs syndrome

For delivery

- Health care support workers
- Health visitors, school nurses, children's nurses

Outcomes

Short term outcomes

- better management of continence issue
- Prevent exclusion from school/ social situations
- timely support for family and child-frequent follow up, telephone access to advice
- individual management plan
- expert care provision
- Reduced need for hospital referral/admission for continence issues

Medium term outcomes

- improvement in continence symptoms
- early intervention for children with continence issues

Long term outcomes

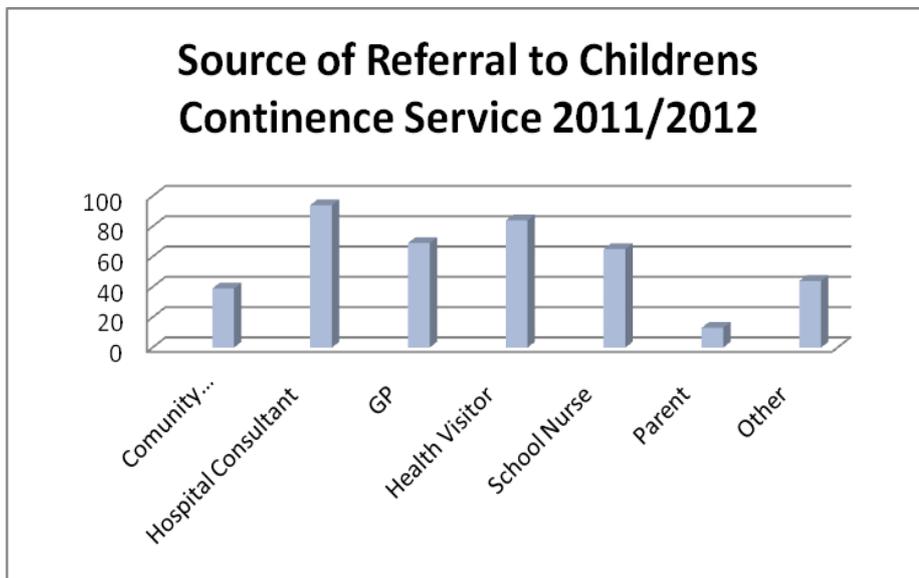
- reduction in number of children with long term continence issue
- Avoidance of unnecessary tests and investigations

- Reduced need for medical referral in management of childhood incontinence

Outcomes for health/education professionals

- skills and knowledge to provide 1st line management of children's continence care
- Access to continence resources-products, leaflets, information
- Reduced referral rates to their service
- Reduced school absence rates

Referral to the Children's Continence Service (Northern Sector)



Source of Referral 2011/2012

| | |
|-------------------------|----|
| Community Paediatrician | 39 |
| Hospital Consultant | 94 |
| GP | 69 |
| Health Visitor | 84 |
| School Nurse | 65 |
| Parent | 13 |
| Other | 44 |

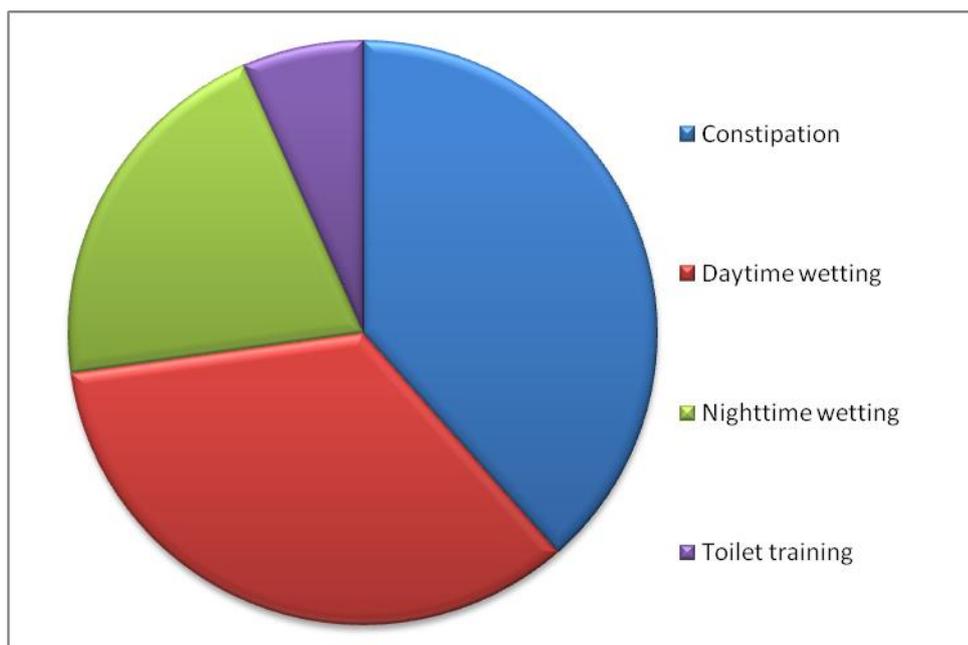
Total 408

The children's continence service operates an open referral system and will accept referrals from health care professionals, education or the parent of a child. For the years covered in this study the service has received approximately 200 referrals per year. Research from the UK suggests that while many people are eligible for continence services, very few actually take advantage of the service available, yet many continence problems are curable or can be managed effectively when the right support and services are in place.. The paediatric continence forum (2012) estimate that 1 in 12 children are affected with bowel and/or bladder problems, yet these are often hidden due to their social stigma.

Almost 33% of referrals to the children's continence service were from hospital and community paediatricians. This means that these children will have had at least one consultant consultation and possibly more. These children could be seen by the children's continence nurse and assessment completed with referral on if necessary, therefore reducing consultant workload and increasing their capacity for other work. Jenny Perez, Director of ERIC (2013) reports that 13000 children (under 19yrs) per annum are admitted to hospital for chronic constipation, stating that 90% of which could be avoided through improved early intervention in community based children's continence services.

Reason for referral to Children Continence Service 2011/2012 (Northern Sector)

| | |
|-------------------|-----|
| Constipation | 157 |
| Daytime wetting | 140 |
| Nighttime wetting | 84 |
| Toilet training | 27 |
| | 408 |



Children are referred to the children's continence service with a variety of continence problems. Some may present with only one condition but often there is combination of symptoms such as day and night time wetting or constipation and daytime wetting.

All children are offered a comprehensive continence assessment with the consultation taking approximately one hour. During this assessment toileting habit, continence symptoms and impact on child's daily activities is considered. The child may also be offered ultrasound scanning of bladder, uroflow studies, urinalysis, and physical examination depending on symptoms. The child and family are offered regular clinic follow up and can contact the nurse by telephone in between appointments if required.

Following assessment the child and family are involved in deciding a suitable treatment plan and the family provided with information on how to promote good toileting habits for all the family to ensure bladder and bowel health. The Paediatric Continence Forum report that children with continence problems feel isolated and fear that others will find out about their difficulties. They have found that having a bowel or bladder condition can reduce social opportunities and can affect mental and emotional health and wellbeing, attainment at school and parent's working lives. Butler (2006) in a study of children with nocturnal enuresis found that parents reported that wetting was a source of family stress, an estimated 30% of parents reported responding to the wetting by punishing their child.

ERIC (2006) estimated that each child who wets the bed every night costs the family £27.50 a week (£1430 per year) in extra washing, bedding and nightclothes and each child who soils (twice daily) costs the family an extra £36 per week (£1872 per year).

Comparison of costs for child with daytime wetting attending nurse led community continence clinic and child attending consultant led hospital clinic

Child is identified with daytime wetting in school nursing health screening questionnaire

Referred to GP

Cost: £32 for 12 minute consultation

Referred to Children's Continence Nurse

Cost: £57 for 60 minute assessment

Referred on to Paediatrician

Cost: £139 for 20 minute assessment

Assessment including post void ultra sound scan of bladder

Assessment including ultrasound scan of bladder and renal tracts

Information and advice. Treatment plan

Review with paediatrician approx 6 weeks after ultrasound scan. Treatment plan.

Cost: £117 for 20 minute consultation

Review with nurse after 1-2 weeks after treatment commenced

Cost: £28.50 for 30 minute and reassessment

Review with paediatrician 6-12 weeks after treatment commenced

Cost: £117 for 20 minute consultation

Total cost: £456

Total cost: £85.50

Cost comparison 2011/2012 (Northern Sector)

140 children referred to the children's continence nurse with daytime wetting.

Of these 140, 36 children had attended consultant led hospital clinic and were referred on to the children's continence nurse for urotherapy.

Cost of consultant led service - £456 (up to and including 1st review appointment) per patient

Total cost : 104 patients X £456 = £47424

140 children referred to the children's continence nurse led clinic with daytime wetting

Cost of nurse led clinic - £88.50 (up to and including 1st review appointment) per patient

Total cost: £11,970

5 children were identified as needing further investigation at the nurse led clinic and were referred on to the Consultant led service.

Cost savings to the Trust of the nurse led service for children with daytime wetting 2011/2012.

(Assuming that those children referred to the children's continence nurse would have been referred to the paediatrician)

£35454/2yr in Northern Sector of Trust

Unit costs for outpatient 1st and follow up attendances are based on the average cost for paediatrics taken from the 2010/11 Payment by Results outpatient attendance tariff. (www.psr.u.ac.uk) This source of data was used as it was not possible to obtain comparative costs within the Trust, however from the data that is available regarding the cost per consultation for specialist nurse within the Trust, the figures are similar.

These figures have not been adjusted for inflation and 2.5% would need to be added for yrs 2011/2012

The cost figures are based on unit costs for staff time and do not include other expenses such as travel and administration costs. This was due to being unable to access equivalent data for consultant's additional costs. The nurse's additional costs can be accessed in appendix.

Comparison of costs for child with constipation and soiling attending nurse led community continence clinic and child attending consultant led hospital clinic

Child is identified with constipation and soiling in school nursing health screening questionnaire

Referred to GP

Cost: £32 for 12 minute consultation

Referred to Children's Continence Nurse

Cost: £57 for 60 minute assessment

Referred on to Paediatrician

Cost: £237 for 20 minute assessment

Assessment

Assessment including plain X-ray of abdomen

Cost: £30

Information and advice. Treatment plan

Information and advice. Treatment plan

Review with nurse after 1-2 weeks after treatment commenced

Cost: £28.50 for 30 minute and reassessment

Review with paediatrician 6-12 weeks after treatment commenced

Cost: £162 for 20 minute consultation

Total cost: £461

Total cost: £85.50

Cost Comparison 2011/2012 (Northern Sector)

157 children referred to the children's continence nurse with constipation and soiling.

Of these 157, 45 children had attended consultant led hospital clinic and were referred on to the children's continence nurse for further advice and follow up.

Cost of consultant led service - £461 (up to and including 1st review appointment) per patient

Total cost : 112 patients X £461 = £51632

157 children referred to the children's continence nurse led clinic with daytime wetting

Cost of nurse led clinic - £88.50 (up to and including 1st review appointment) per patient

Total cost: 157 X £88.50 = £13894

Cost savings to the Trust of the nurse led service for children with constipation and soiling 2011/2012 (assuming that those children referred to the children's continence nurse would have been referred to the paediatrician)

£37738/2yr in Northern Sector of Trust

The costs for children being treated with constipation differ from that of children with daytime wetting as the cost of seeing a gastroenterology consultation is higher than a general paediatrician.

It should also be noted that children attending the consultant led clinic will have an abdominal x-ray taken. NICE guidelines (2010) on the management of childhood constipation state that abdominal x-ray is not required in the diagnosis of constipation in children.

Also two children, seen by the nurse led service required referral on to the regional unit for further investigation and biopsy.

Unit costs for outpatient 1st and follow up attendances are based on the average cost for paediatrics taken from the 2010/11 Payment by Results outpatient attendance tariff. (www.pssru.ac.uk) This source of data was used as it was not possible to obtain comparative costs within the Trust; however from the data that is available regarding the cost per consultation for specialist nurse within the Trust, the figures are similar.

These figures have not been adjusted for inflation and 2.5% would need to be added for yrs 2011/2012

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Conclusion

This study demonstrated that there is a significant economic benefit to a nurse led children's continence service. The economic analysis concentrated on the comparison of a nurse led clinic and paediatric consultant led service. The figures provided are for the Northern Sector of the Trust, but it is believed that the referral figures and work of the nurse led continence service in the Southern Sector of the Trust is equivalent to that in the Northern Sector.

This study did not consider the cost savings to the family when incontinence is managed or cured and the benefits to providing a clinic in a community setting allowing easy access to families without the need to travel long distances. Another aspect of economic benefit which would be useful to consider for further study is how the inter- disciplinary working of the service reduces the social and emotional impact of the children's incontinence, allowing them to attend school and social activities.

Although this study did not include data on patient symptom outcome, an audit of user satisfaction with the service (2012)(appendix) indicated that 100% of service users were satisfied or very satisfied with the service provided.

Other studies have demonstrated that children with continence problems who attend a nurse led clinic are equally as, if not more likely to be cured of their continence symptoms, than those attending a consultant led paediatric clinic (Burnett et al, 2004; Borrie et al, 2002). This highlights that a nurse led is effective and that clinical outcomes are least equivalent if not more effective than consultant led services for children with continence problems.

Other benefits of the nurse led service are apparent, however they are not possible to cost. This includes the provision of education to health care and education professionals on early intervention for children with continence difficulties and health promotion activities to promote healthy bowel and bladder; which result in the avoidance of need to refer on to other agencies and provision of continence products. Also the benefit to the patient of having care provided by an independent nurse prescriber, ensuring seamless care, increasing medication compliance and concordance and reducing the need for General Practitioner consultant to obtain prescription and subsequent GP review while on medication.

One important aspect of the service which could demonstrate significant economic benefit, particularly for the Trust is the use of containment products for children with continence issues. Current policy within the Trust allows containment products to be made available to children with continence difficulties from the age of 3yrs, following continence assessment. A study by Rogers (2008) found that the number of children requiring containment products was significantly reduced when health care professionals, with skills in continence assessment, undertook the assessment and provided treatment plans for promoting toilet training.

In this study it was found that one person responsible for product provision, with health visitors, CCNs and school nurses involved with potty training and programmes to support toilet skill development increased the number of children who are toilet trained.

Whilst this study demonstrates considerable cost savings by utilising a nurse led continence service, it can be assumed that further development of the nurse led continence service could lead to larger numbers of children attending the nurse led service without need to attend consultant services. It is not possible to be precise regarding the potential numbers of children due to the differing coding utilised within the hospital; and awarding a continence code could be considered in order to ascertain the number of children referred with continence difficulties.

It could also be considered that consultants are increasingly referring children with continence difficulties on to the nurse led service for further management, thus reducing the need for hospital follow up, further increasing the potential for cost effectiveness. This also has positive treatment outcome benefit for the child , as the child will continue to receive review for as long as their condition persists and they engage with the treatment plan.

However in order to maintain capacity and effectiveness within the nurse led continence service there is a need to expand the service. Although the data were not analysed in respect of first clinic appointment waiting times there is a waiting time of approximately 8 -10 weeks for a first appointment. If there were an increase in referral numbers this would increase the waiting times for first appointment and the ability to offer regular review would be compromised. NICE (2012) provides a template for modelling resources needed to maintain children's continence service levels based on population numbers. It was not used in this study as the data is not equivalent, but could be used to help determine future service requirements.

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Childrens Continence Service Audit December 2012

Introduction

The need for integrated continence services was first highlighted in Good Practice in Continence Services (Department of Health, 2000). Using the policy target in Good Practice in Continence Services (DoH, 2000) as a criterion, effective interventions for children and young people should include:

- Early assessment by a suitably trained health professional in consultation with parents and other carers, including school staff;
- Assessments that specify the child's problem;
- A clear treatment and management strategy.

Standards of care for children with continence issues are contained within a number of guidelines. These are based on evidence from literature and best practice and obtained from clinical and research studies. (NICE, 2010; NICE, 2011, ERIC,

The children's NSF recommended that: 'An integrated community-based paediatric continence service, informed by Good Practice in Paediatric Continence Services, ensures that accessible, high-quality assessment and treatment is provided to children and their parents/carers in any setting, including, for example, looked-after children and children at boarding schools' (DH, 2004).

The ultimate aim of the children's continence service is to put in place a comprehensive, proactive paediatric continence promotion service.

This audit assesses user satisfaction with the children's continence service to determine if the care given was perceived as accessible, high quality and meeting the needs of those using the service.

Aims and Objectives

- To determine user satisfaction with the children's continence service.
- To measure the time frame between referral date and date of first appointment offered.
- To determine if information provided on the referral document was appropriate.

- To determine source of referral to the children's continence service.
- To assess the main reason for referral to the children's continence service and the age range of the children referred.

Conclusions

- Referral

76% of patients were offered an appointment within 12 weeks of the referral being made. This is within the time limit set by DOH for professionals allied to health.

9% were offered an appointment within 16 weeks of referral date, and the remaining 15% were unsure or did not record the data.

97% of patients were aware they had been referred to the children's continence service.

71% had been provided with information about the service before their first appointment, and 94% found this information to be helpful.

- Clinic

99% found the clinic venue to be suitable, with 81% commented that appointment times were always suitable and 8% often suitable. 86% of patients were always seen on time, and 95% thought that the appointment length was about right, with 100% agreeing or strongly agreeing that they were given sufficient time in the session.

- Consultation and Treatment

99% of patients felt that their problem was understood by the advisor and that their concerns were listened to. 91% felt that the treatment suggested was appropriate for their child; with 5% being unsure and 4% waiting to commence treatment. 100% agreed or strongly agreed that treatment was explained adequately, with 96% agreed or strongly agreed that they felt involved in making decisions about their treatment. 89% of patients were happy with the way treatment progress was monitored and 93% found the monitoring charts easy to understand and use.

Overall 100% of patients who completed the questionnaire were satisfied or very satisfied with the service they received at the children's continence clinic.

- Making a referral

98% of health care professionals were aware of the service and 94% knew how to make a referral. 69% were aware of the guidelines for referral and 66% knew the information required on the referral form. 93% knew how and where to contact the continence nurse and 92% had no difficulty making contact with the nurse.

30% stated that they had referred to the continence service instead of to another service

- Quality of the service

96% felt that the service is of benefit to the children and 92% consider the service to be of a high quality; with 96% recommending the service to patients.

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