

Good Practice in Paediatric Continence Services – Benchmarking in Action



Foreword

I am delighted to be able to write a foreword to this publication which supports and highlights the issues relating to service provision *specifically* for the management of *paediatric continence* in line with the Essence of Care toolkit. It focuses on the core and essential aspects of care in delivering a quality continence service for children.

It was highlighted by the "Children's Continence Action Group" that there was a need to have a unified approach to service provision in line with the Essence of Care benchmarking "best practice" toolkit.

Essence of Care is about celebrating and sharing good practice. This supporting publication demonstrates ways of looking at sustaining improvement in service delivery for *paediatric continence* across the health economy, highlights examples of benchmarking in action and outlines

within each of the factors key issues for consideration when addressing a "whole child" approach so that children with continence problems can be treated appropriately.

I am confident that by the enthusiasm that has been demonstrated by Paediatric Continence Advisors nationally, in writing this document it will prove to be a valuable resource to help improve the quality of service provision for children with continence problems.

John Badham

Programme Director for Essence of Care
Modernisation Agency



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Good practice in Paediatric Continence Services – Benchmarking in Action

Introduction

A recent national survey to identify 'best practice' in paediatric continence promotion found that overall the standard of service provision was poor with little evidence of a child centered approach or integrated working. The 'Children's Continence Action Group' is a group of like minded professionals who got together to review the provision of paediatric continence services throughout the country.

Each Primary Care Trust (PCT) should commission an integrated community based paediatric continence service. This is based on a wealth of evidence such as the 'Essence of Care' (DH 2001), Good Practice in Continence Services (DH 2000), Minimum Standards For Enuresis, Constipation and Soiling and the soon to be published Minimum Standards for children with learning difficulties (Enuresis Resource and Information Centre).

Prevalence

Paediatric continence issues covers the whole spectrum of bowel and bladder problems and can range from infants born with life threatening congenital bowel and bladder abnormalities to the adolescent who feels totally alone and socially isolated because of persistent wetting or soiling problems.

It is estimated that persistent bedwetting affects approximately 1 in 6 five year olds, 1 in 7 seven year olds, 1 in 11 nine year olds and 1 in 15 eleven year olds, with proportional decreases between these age bands (Butler, 1998). Day-time wetting affects about 1 in 25 five year olds, 1 in 50 seven year olds, 1 in 100 eleven to eighteen year olds (Hjalmas, 1992). Soiling affects about 1 in 30 five year olds and 1 in 75 six to ten year olds and 1 in 100 eleven to eighteen year olds (Doleys et al 1981). There is estimated to be 900,000 children and young people between the ages of 5 and 18 years affected in the United Kingdom.



There is well-established evidence that bedwetting reduces children's social opportunities, causes them to feel "different" from others and to fear that their "secret" will be discovered and they will be teased or bullied by their peers. A study by Williams (1996), interviewed 2,962 children from primary schools in Sheffield, found a strong association between bedwetting and bullying. As adults some still felt socially disadvantaged, even if the problem had resolved (Stromgren and Thomsen, 1990).

It is very likely that children and young people with the more "visible" problems of day-time wetting and soiling suffer even more than children with bedwetting, but there has been little research in this area.

Children with learning and or physical disabilities experience particular continence needs that we believe are not being adequately met, particularly at school. A Joseph Rowntree qualitative study of the social effects on children and young people aged 8-22 years with soiling difficulties, found widespread



public ignorance; at school, inadequate facilities and support caused the children concerned to be anxious and fearful (Cavet, 1998).

There is good evidence therefore regarding the need to review paediatric continence services and implement 'Best Practice'. The Essence of Care benchmarking was launched nationally in February 2001. There are now 9 benchmarks that focus on fundamental aspects of care, one of which is continence and bowel and bladder care.

Example of Benchmarking in action

Various Trusts around the country have looked at and scored their practice against the Continence benchmark, one Trust in particular has specifically looked at benchmarking their paediatric continence service with the 'best practice' statements viewed from the point of view from the child and their families. Scores were then collated and discussed at a comparison group meeting. It became obvious that whilst the service had areas of good practice, this was found to be variable and inconsistent across the whole district.

The service was based on the 'medical model' and was doctor led with little nursing input. The referral routes were not known to all and children often needed to be 're-routed' after referrals to the wrong service, the patients journey was definitely not clearly defined. Advice given was ad hoc and not always

evidenced based with an overall very variable staff knowledge base.

As a result of this the Child Health directorate are now undertaking a review of their service. This has included looking for areas of expertise, a neighbouring Trust has developed an excellent paediatric continence service and their lead is helping inform the Trust of ways the service may develop, utilizing their knowledge and experience developed over the years so pitfalls can be avoided.

Training and awareness sessions are being organized for staff in all areas. Information packs and patient information leaflets are being devised, referral routes are being made more robust and the service reviewed to include a more multidisciplinary focus and ensure the service is truly integrated across all sectors.

Participating in the benchmarking process clearly identified where problems lay and has provided a structure to help the service to redevelop, ensuring that the service is patient centred and will work 'smarter' and the child's journey will be more clearly defined and informative, benefiting the individual child and family.

Another Trust identified that although there were good areas of practice it was very fragmented with the risk those children were 'falling' into the gaps between services. They are now working together to develop services under one 'umbrella' which will provide a holistic approach, equitable service and



single assessment. It is envisaged with careful planning and working together that this will reduce the cost, for example, of disposable products for the PCT's and improve the quality of life for these children and their parents and or carers. An early start to the process and careful planning will hopefully deliver an efficient and effective service and long term financial benefits for all PCT's with uncalculatable benefits for the child.

Paediatric continence services should therefore look towards developing a 'whole child' approach so that children with complex problems such as day and night time wetting or constipation and bed-wetting can be treated appropriately.

Although the aim is for children facing continence challenges to be managed in the community, the acute or hospital setting can have a role to play with respect to management. Distinguishing between physiological and functional difficulties remains important and hospital settings have access to diagnostic imaging/assessment tools with some having developed specialist outpatient assessment and treatment resources, which are often nurse led. Intervention programmes can be co-ordinated through nurse led clinics with open access referrals. Integration back into the community can be facilitated with good communication pathways and therefore offer an effective and equitable service for children facing continence issues. Such a service is currently being developed for children with wetting problems between Alder Hey Hospital Liverpool (Royal Liverpool Children's hospital NHS Trust) and neighbouring Knowsley PCT.



Preparing for the future

The Department of Health in conjunction with the Children's and Young Person's Unit (CYPU) is currently working with 10 sites around the country to develop the Identification Referral and Tracking project (IRT). This aims to develop early identification and follow up for children at risk of exclusion because of health or social issues. Children with wetting and soiling problems quite clearly would fall within this 'at risk' group.

The Children's National Service Framework (NSF), may not have set 'targets' but will certainly lay down recommendations for best practice in continence services. PCT's need to ensure that services are developed in line with current and proposed service recommendations.



Why change is needed

'Ninety per cent of all patient journeys begin and end in primary care...' 'Liberating the Talents', DH 2002

The need for an integrated service

Good Practice in Continence Services, DH, 2000

Older persons National Service Framework, DH 2001

Current recommendations are that services should:

- Be based upon and evolve from local continence advisory services
- Ensure users and carers are involved in the planning, provision and audit of services



developed for children with 'special needs', these children should have the same access, where appropriate, to all investigation and treatment programmes as their mainstream peers

By looking at service provision in line with the Essence of Care benchmarking 'best practice' tool, Trusts will be able to clearly identify service provision deficits. By sharing 'best practice' with other areas and linking in to work together to improve services, Paediatric continence promotion services nationally should cease to be the Cinderella service of the past, ensuring the best possible treatment outcomes for those children in our care.

- Ensure that there are systematic efforts to identify cases of incontinence, regardless of where an individual may be residing
- Enable treatment, based on assessment, to be delivered in the most appropriate setting, which is usually primary care in the first instance
- Be cohesive and comprehensive covering:
 - urinary and faecal incontinence
 - adults and children
 - people resident in their own homes and elsewhere
- allow easy access to specialist care when it is needed

It is important that services should be fully inclusive and accessible for all children regardless of age or disability. Separate services should not need to be



The Essence of Care for Paediatric Continence Promotion and bladder and bowel care

Agreed patient focused outcome
Patients' bladder and bowel needs are met

Factor 1 - Information for children/families/carers

Patients and or carers have no evidence based information about bowel and bladder care

Benchmark of best practice

Patients and or carers have free access to general evidence based information about bowel and bladder care

E  A

Indicators of best practice for factor 1

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- A range of child focused information is available for children, young people their family and carers that includes national and local information and is available in a variety of formats to suit their individual needs such as story books, dolls, pictures, videos and CD ROM's
- Any measures are taken or promoted to ensure awareness and accessibility of available information to children, young people their family or carers
- User acceptability of information is audited, surveyed, analysed and that there is evidence of utilization of feedback from this
- An evidence-base for information is available and how this is evaluated to ensure it is up to date and consistent



Examples of working towards best practice

"To improve the service for children we are developing ... information for children and parents"
Sandra McDonald Continence Advisor (West Lancashire PCT)

Leaflets regarding soiling have been developed and also available are ERIC booklets, Enuresis CD ROM, and various story books for the children to read Dr Ursula Butler (Sheffield Children's Trust)

"...a quarterly newsletter is sent out with relevant information and new ideas. There is also an annual user group exhibition" Julia Jefferies (Paediatric Continence Advisor Bedfordshire)



Factor 2 – Access to Professional Advice re Continence and Bladder and Bowel Care

Patients do not have access to professional advice re professionals who can meet their continence needs

Benchmark of best practice

Patients have direct access to professionals who can meet their continence needs and their services are actively promoted

E  A

Indicators of best practice for factor 2

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Professional advice and services are available that meet the individual continence needs of children and young people
- Self referral is possible for children and young people, their families and cares to access services
- Policies/Procedures/Referral protocols are available to specialist paediatric services
- Response times for referrals or appointments are met and meet ERIC guidelines
- Any provisions have been made to ensure accessibility to continence services, particularly from vulnerable groups, children with special needs
- There are any barriers that prevent needs being met locally such as language, special needs, lack of interpreters, waiting lists, products, equipment, lack of knowledge and interpersonal skills and what is being done to address these
- Strategies incorporate education and training programmes for health care personnel to enable them to provide advice
- Children with special needs e.g. learning, disabilities can fully access all services e.g. enuretic clinics



Examples of working towards best practice

Children with special needs have open access to the Enuresis/Encopresis Clinic the same as their mainstream peers and have full assessment and trial of potty training as well as investigations if clinically indicated. Dr A Crocket (Forth Valley Scotland)

“Joint clinics with Consultant Paediatrician for all children with soiling and continence problems”
Carol Potter Community Nurse Specialist (Colchester PCT)

“...a community paediatric continence specialist practitioner has been appointed from May 2003...”
Mandy Wells Senior Nurse Specialist (Camden and Islington PCT)

“Community School Nurse and Behavioural psychologist run joint clinic ...offering advice, guidance and intervention...on enuresis, daytime wetting, encopresis, soiling and toilet training” Viv Allison,
Community School Nurse West Berkshire

“...clinic was developed as ERIC guidelines in ‘Childhood Soiling” Warrington PCT

“Paediatric continence advisor in post since Aug 01...Mandatory training on paediatric continence management for H.V.I.S.N's. Joint Clinic with Paediatrician for encopresis and soiling.” Julia Jeffries
(Paediatric Continence Advisor Beds)

“Open referral community continence clinic...run jointly by paediatric continence advisor and consultant community paediatrician with clinical psychologist and dietetic input...information regarding the clinic is given to parents/carer in A&E when child presents with severe constipation.” Dr Ursula Butler
(Sheffield Children's Trust)



Factor 3 - Assessment of individual patient

Patients are not asked a trigger question related to bladder and bowel continence needs within their general health assessment

Benchmark of best practice

Patients positive response to the trigger question always leads to an offer of an initial bladder and bowel continence assessment which if accepted by the patient is completed

E  A

Indicators of best practice for factor 3

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- A trigger question determines assessment and there is evidence of audit to ascertain whether trigger questions were asked
- Trigger questions are asked as part of for example, school health checks, routine admission, opportunistic screening
- The use of trigger questions is promoted amongst colleagues and other team members
- The child's or young person's understanding or acceptance of the trigger question is assessed, describe any adaptations made to the trigger question used
- Assessment tools have been adapted for use within Paediatric groups



Examples of working towards best practice

School nurse school entry questionnaire asks if problems with enuresis or soiling and if positive triggers interview with school nurse for initial assessment. Dr Ursula Butler (Sheffield Children's Trust)

...most referrals come from H.V.I.S.N's as a result of trigger questions being asked Dr Aysel Crocket (Forth Valley Health Board Scotland)

All children presenting to the paediatric continence service have an assessment of both their bladders and bowels regardless of what presenting problem is (this is because a high incidence of children with bed wetting also have underlying asymptomatic constipation) June Rogers Paediatric Continence Advisor (Knowsley PCT)



Factor 4 – Planning, implementation and evaluation of care based on the bladder and bowel assessment (to be completed only if an assessment has been performed)

There are no patients' plans of care to meet the bowel and bladder needs identified in the continence assessment

Benchmark of best practice

The effectiveness of patients' care is continuously evaluated and leads either to the patients' needs being met or the modification of the care plan (e.g. referral on)

E  A

NB. It is expected that care is evidence-based and planned jointly with the patient, family and or carers

Indicators of best practice for factor 4

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Professional advice and services are available that meet the individual continence needs of children and young people
- Self referral is possible for children and young people, their families and cares to access services
- Policies/Procedures/Referral protocols are available to specialist paediatric services
- Response times for referrals or appointments are met and meet ERIC guidelines
- Any provisions have been made to ensure accessibility to continence services, particularly from vulnerable groups, children with special needs
- There are any barriers that prevent needs being met locally such as language, special needs, lack of interpreters, waiting lists, products, equipment, lack of knowledge and interpersonal skills and what is being done to address these
- Strategies incorporate education and training programmes for health care personnel to enable them to provide advice
- Children with special needs e.g. learning, disabilities can fully access all services e.g. enuretic clinics



Examples of working towards best practice

Reviews in special school by school nurse or community paediatrician identify continence issues and generate appropriate referrals. Dr Ursula Butler (Sheffield Children's Trust)

"Audits have been carried out regularly against ERIC standards" Warrington PCT

"Support continues on an individual basis...more formal investigations...are arranged as appropriate" Caroline Sanders Paediatric Urology Nurse RLCH Alder Hey

Annual Audit in the clinic is carried out and support continues on an individual basis as well as in the clinic. Dr A Crocket (Forth Valley Scotland)

Locally agreed treatment guidelines and careplans have been developed. June Rogers Paediatric Continence Advisor (Knowsley PCT)

Factor 5 - Education for professional assessors and care planners

Patients are not assessed or do not have care planned by a health professional

Benchmark of best practice

Patients are assessed and have care planned by professionals who have received specific continence care training and are continuously updated

E  A

Indicators of best practice for factor 5

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Roles and responsibilities are defined for those carrying out assessment and planning of care, state who assesses and plans care
- Children are assessed and have care planned by professionals who have a paediatric background and who have received specific continence care training and are continuously updated
- Initial and ongoing education and training opportunities, programmes, policies and training analysis, peer group review, supervision and personal development plans are used, state use of peer group review/supervision
- Training packages, information and communication channels are used, training records are maintained
- Children and young people's views and expectations are included in any training programme including links with self-help or user groups
- The impact of any training is assessed and evaluated
- The education content and outcomes includes consideration of any individual needs i.e. children with learning needs, children, parents or carers that have language needs



Examples of working towards best practice

"A multi-disciplinary workshop was held... for children with bowel and bladder problems...as a result a...study day with presentations from experts in the field...was held" Rona Mackenzie, Clinical Nurse Specialist – Continence, Epping Forest PCT

"Formed a regional group...multi-professional...with speakers covering requested topics." Mary White Trent Region

All children in Bedfordshire are assessed by paediatric Continence Advisor who holds Specialist Community Practitioner degree (School Nurse Pathway) and who has completed Continence Promotion for Children with Bladder/Bowel dysfunction level 3 (formally ENB R92). She also attends regular study days and conferences... Julia Jeffries Paediatric Continence Advisor (Bedfordshire)

Annual Workshops are held with speakers covering several relevant topics Dr A Crocket (Forth Valley Scotland)

All children who are perceived to have potential problems becoming toilet trained have early assessment to identify and address any toilet skill deficits. June Rogers Paediatric Continence Advisor (Knowsley PCT)



Factor 6 - Promotion of continence and a healthy bladder and bowel

There is no attempt to promote patients' continence and a healthy bladder and bowel

Benchmark of best practice

All opportunities are taken to promote continence and a healthy bladder and bowel among patients and the wider community

E  A

Indicators of best practice for factor 6

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Any 'risk' groups are identified locally for example, children with special needs, school age children, post operative, and post procedure and what you are doing to target these groups.
- Inter-professional or interagency working is assured and how this promotes continence
- The content (evidence-base) and format of promotion strategies e.g. videos, pictures, story boards, written including how they are used to promote knowledge and understanding within the wider community, including hard to reach communities e.g. children with special needs black and minority ethnic communities
- Measures to promote continence services, including links with self help, user groups and health promotion units, with the displaying and use of posters and leaflets
- Children and young people with special needs have the same access to all services as their mainstream peers
- Audits are undertaken, educational links and ongoing research
- Links with local user or self help groups are used to raise awareness
- Any local awareness initiatives, including use made of national promotional opportunities e.g. Healthy school campaigns, 'Water is cool in school' campaign, National Continence Week
- Practitioners are actively involved in raising awareness and promoting healthy bladders and bowels among all children, their families/ carers and the wider community e.g. schools



Examples of working towards best practice

Multi-disciplinary team developed the 'Water Wise Guidance' for schools Warrington PCT

Paediatric continence nurse has developed training package on constipation and soiling to deliver to small groups of interested people eg School nurses, health visitors, Practice Nurses and teaching staff in Special schools. Dr Ursula Butler (Sheffield Children's Trust)

Education sessions on toilet training/healthy bladders and bowels in children with special needs at inclusion nurseries. Julia Jeffries PCA (Bedfordshire)



Factor 7 - Access to continence supplies

Patients do not have access to supplies that assist in the management of their incontinence

Benchmark of best practice

Patients have access to appropriate 'needs specific' supplies to assist in the management of their incontinence

E  A

Indicators of best practice for factor 7

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Health care personnel are proactive in anticipating the needs and preferences of children, their family and or carers and that choice is not restricted to number and type of product
- Sufficient time is given to enable children to communicate their needs and preferences.
- Explicit or expressed consent is obtained from patients prior to treatment or care
- Patients have access to specialist knowledge and skills and have access to supplies that assist in the promotion of continence
- Technology is available and is used to meet patient needs, for example, electronic prescriptions
- The use of services is monitored for example, by regular audit
- Arrangements are in place for equipment cleanliness, maintenance and replacement
- Children have access to appropriate 'needs specific' supplies to assist in the management/promotion of their continence and they are only supplied following a full documented assessment
- Children with special needs have access to specialist equipment they may require such as musical potties, wetting alarms



Examples of working towards best practice

Once children with special needs have become clean/dry during the day they are referred to the enuretic clinic for assessment. Use of wetting alarms to establish a voiding pattern/baseline prior to toilet training programme. Julia Jeffries Paediatric Continence Advisor (Bedfordshire)

All children are seen and assessed by Paediatric Continence Advisor. Advice given regarding healthy bladder/bowels and suitability for toilet training before pad provision made.

Children and their families are offered a choice of product if appropriate and the needs are continually reassessed. June Rogers Paediatric Continence Advisor (Knowsley PCT)

All continence equipment for loan is held centrally and details are kept on a computer data base which facilitates tracking. All equipment is cleaned and checked as per national health and safety guidelines.

June Rogers Paediatric Continence Advisor (Knowsley PCT)



Factor 8 – Education of the care deliverers

Patients are cared for by carers with no continence training

Benchmark of best practice

Patients are cared for by carers who have undertaken continence care training which includes ongoing updating

E  A

NB. Education should involve regular practice and peer review.

Indicators of best practice for factor 8

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Children are cared for by practitioners who have a paediatric background
- The training needs of those who give care are assessed and how this is carried out to ensure that those giving care have undertaken continence care training which includes ongoing updating
- Intended learning outcomes are clearly identified and the impact of training is assessed and evaluated
- Peer group review, supervision and personal development plans are used
- The views and expectations of children and young people are included in training programmes, including links with self-help or user groups
- Appropriate training packages, information and communication channels are used
- Training of children and young people or their parents and or carers or support groups takes place and that a range of teaching aids is available for children with special needs
- There is a facility where staff can shadow 'local experts'



Examples of working towards best practice

"Training and co-ordination of the school nurses to run follow-up enuresis clinics" Mandy Wells, Senior Nurse Specialist Camden and Islington PCT

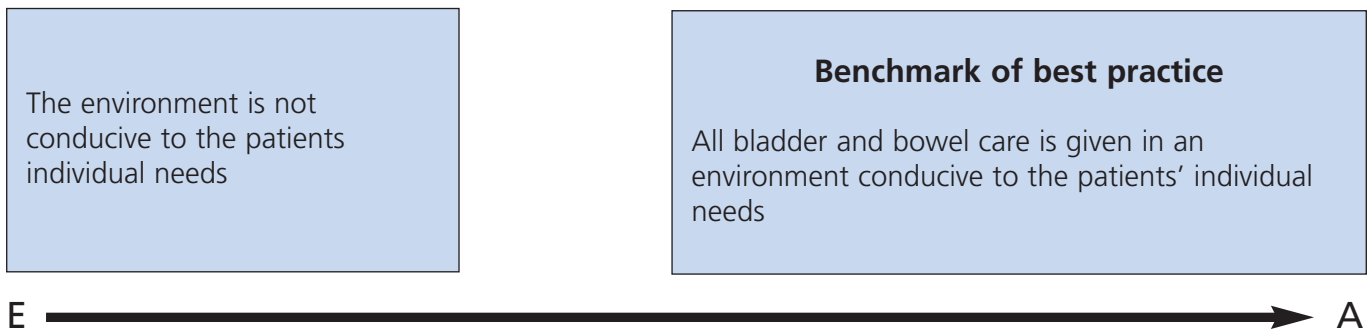
"...set up a training programme for school nurses and health visitors." Linda Winson Continence Advisor North East Wales NHS Trust

"...we provide training for school nurses and schools..." Sandra McDonald, Continence Advisor, West Lancs PCT

Mandatory training on continence management for all H.VIS.N. Julia Jeffries PCA (Bedfordshire)

"Area Continence advisor and I work together to provide training for health Visitors and School Nurses." Dr A Crocket (Forth Valley Scotland)

Factor 9 – A physical and social environment conducive to continence and a healthy bladder and bowel



NB. Consideration of individual needs i.e. children with 'special needs' is paramount however this may need to be balanced with meeting the needs of other users of the same facility. (Use with Privacy and Dignity Benchmark)

Indicators of best practice for factor 9

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Attempts are made to make the environment child friendly and adaptable for different age groups
- The environment is conducive for the child's individual needs such as lighting, cleanliness, heating adaptations, that curtains meet, facilities are age related, religious and cultural sensitivities
- The views on the environment are sought from children and young people, their families or carers and are acted upon and action is taken to remove any barriers
- Consultation with specialist continence professionals has taken place in assessing the environment
- The environment is adapted to meet the individual needs of patients for example, children with disabilities or mobility problems
- There is evidence of attempts to make the environment conducive to the individual, such as disability access



Examples of working towards best practice

Adaptation of the Utrecht model...bladder retraining...is run in a child friendly environment. Caroline Sanders Urology Nurse (RLCH Alder Hey Liverpool)

Continence Clinics are held throughout Special Schools in Bedfordshire or in mainstream schools as appropriate. Bowel clinics are held in child development center. Julia Jeffries Paediatric Continence Advisor (Bedfordshire)

The inclusion of a nursery nurse as part of the paediatric continence team has led to the development of a range of child friendly record/incentive charts with prizes and rewards for achievable targets. June Rogers Paediatric Continence Advisor (Knowsley PCT)

Factor 10 - Patient to Patient Support

Patients and or carers have no access to other patients and or carers for support

Benchmark of best practice

Patients and or carers have the opportunity to access other patients who can offer support and this is actively promoted

E  A

Indicators of best practice for factor 10

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Children and their families and or carers have the opportunity to access patient/family support groups both locally and nationally.
- Information about support groups is given to children and families
- Measures have been taken to set up or support a local self-help or user group and whether there are any barriers to this support
- Links are in place between services and local groups
- Strategies are in place to put families in touch with each other and they are aware they can contact others



Examples of working towards best practice

“Setting up of soiling/continence support groups for parents of children with learning difficulties...”

Carol Potter, Community Nurse Specialist, Colchester PCT

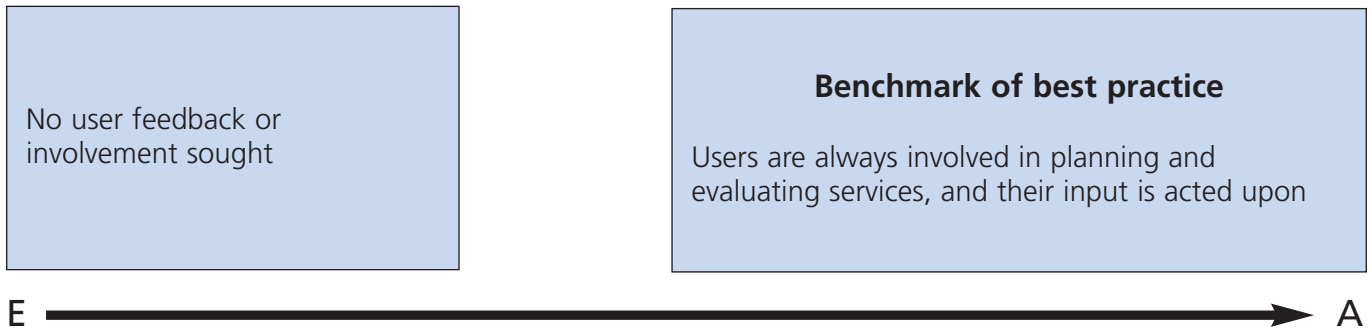
Children and their families are given information regarding ERIC. Dr Ursula Butler (Sheffield Children's Trust)

Parents and schools have open access to the clinic by telephone and are given ERIC Helpline information. We are in the process of starting a support group run by one of the parents.

Dr Crockett (Forth Valley Scotland)



Factor 11 - User involvement in service delivery



Users whenever possible should be involved in all aspects of care planning and delivery. (The term 'user' relates to patient, relative, family, or carer)

Indicators of best practice for factor 11

To stimulate discussion about best practice in your comparison group, you may find it helpful to consider whether:

- Methods are used to secure children and young persons involvement e.g. focus groups, user forums, etc to include consideration of religious, cultural, language and age related and special needs issues
- The views of children, their family or carers are sought and how satisfaction with continence services is assessed and how complaints are addressed
- There is evidence of inter-agency involvement and networking with all stakeholders
- Strategies are used to involve users from isolated or hard to reach communities e.g travelers, 'looked after' children
- Both children's and parent/carers views are sought when planning and evaluating services and their input is acted upon



Examples of working towards best practice

Annual User group exhibition. Quarterly questionnaire re deliveries. Discharge questionnaire measuring user satisfaction. User group. Julia Jeffries PCA (Bedfordshire)

Looked after children are referred via social work department, GP's or School doctors/ nurses to the enuresis/encopresis clinic. Follow up is organized to meet the individual needs.

Travellers also referred via similar routes are lost to follow up when they leave the area. However, follow up is attempted by mobile phone reviews if the family have one, and are encouraged to return to the clinic when they are back in the area.

Families and children's views are always sought and explored from the first visit (especially if the children are old enough to give an account of their views and feelings. Dr A Crocket (Forth Valley Scotland)



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email info@eric.org.uk
website www.eric.org.uk

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