



Good practice in continence services

Contents

Executive :	•	
Section		
1.	Introduction	4
2.	The impact of the problem	6
3.	Continence services	10
4.	Targets for primary and community teams	17
5.	Targets for health authorities and primary care groups	20
6.	Targets for health and local authorities: children	22
7.	Targets for health and local authorities: residential and nursing care	24
8.	Targets for in-patients	27
9.	Implementation issues	31
Annexes		
1.	Members of the groups	33
2.	Continence product supplies	37
3.	Information issues	40
4.	Key documents	42

Executive summary

Prompt, high quality, comprehensive continence services are an essential part of the NHS. Incontinence is a treatable condition. But in 1999 the Audit Commission reported that "In practice district nurses implement a conservative care plan focused on managing the problem rather than treating the underlying cause." Children, young mothers, people with learning or physical disabilities and older people all experience problems with bladder and bowel management, and sometimes, both. In some situations as many as 1 in 7 women aged 45–64 living at home may have problems with incontinence.

An effective range of services needs to be available for people with continence problems. In 1998 a working group was set up to look at continence services and advise on guidance. The group concluded that organising continence services in an integrated way that focuses on identifying patients, assessing their condition and putting appropriate treatment in place is essential. This guidance sets out a model of good practice to help achieve more responsive, equitable and effective continence services to benefit patients. It aims to:

- raise awareness of professionals to the problems of continence;
- provide practical guidance for the NHS on the organisation of continence services across primary, acute and tertiary care;
- provide advice on the individual assessment and treatment of continence by primary care and community staff; and
- describe targets that can be developed locally.

Health authorities, primary care groups, and when they are established, primary care trusts and NHS Trusts should work together, through their Health Improvement Programmes and long term service agreements, to ensure that people with continence problems are identified, assessed and get the treatment they need.

Clinical governance provides the challenge posed by new statutory duty of quality to transform the delivery of primary, hospital and community care so that consistently better outcomes are produced for patients.

1. Introduction

- 1.1 This review of continence services was instituted in 1998 by the then Parliamentary Under-Secretary of State, Mr. Paul Boateng. The Working Group was charged with updating the guidance on continence services originally issued in 1991 by the Department of Health (ML(91)1). To ensure the Group was properly representative, key organisations active in this field were invited to nominate representatives. The membership of the Group is shown in Annex 1.
- 1.2 Continence services exist to meet the needs of the men, women and children who are incontinent of bladder and bowel. They are frequently:
 - disabled by, embarrassed and often ashamed of their condition, keeping it secret from even those closest to them;
 - reluctant to seek help within the family and need encouragement to seek advice from health professionals;
 - unaware of the treatments available to cure or manage their condition.
- 1.3 The Group's aim is to ensure the nationwide availability of high quality services for people with incontinence by:
 - highlighting the extent of the problem;
 - setting out clear and achievable targets for service;
 - giving advice about the clinical and managerial approaches which will ensure that the targets are met;
 - setting out an approach for implementation with systematic processes for monitoring progress.
- 1.4 The Group has drawn heavily on the experience of the best of the existing services and, where it has been available, research evidence to support the guidance.
- 1.5 In developing this guidance the Group has been determined to use the opportunity of current changes in healthcare delivery to recreate coherent services; emphasise collaboration rather than competition and reduce geographical variation.

New NHS

- 1.6 In carrying out the work the Group took into account the opportunities afforded by the new guidance that has been issued to the NHS. In particular, note was taken of:
 - White Paper 'New NHS: modern; dependable';
 - Approach to quality as outlined in the document 'A First Class Service: Quality in the new NHS';

- Inclusion of promoting independence in 'Modernising Health and Social Services' the national priorities guidance for 1999/2000 to 2001/2002;
- Better services for vulnerable people, EL (97)62 / CI (97)24;
- Health improvement programmes, HSC (98)167 / LAC (98)23;
- National Service Framework for Older People;
- Social Services White Paper 'Modernising Social Services',
- For learning disabilities, Signposts for success;
- "Fit for the future" the consultation document
- 1.7 Together with Policy Directions set by other Departments and Cross Departmental initiatives including:
 - National Carers Strategy;
 - The Green Paper 'Supporting families'.
- 1.8 The style and content of the guidance has taken into account the important new changes in NHS management and organisation. In particular, the Group has acknowledged:
 - the role of primary care groups/primary care trusts in the commissioning and development of services;
 - clinical governance mechanisms for ensuring local delivery of high quality clinical services;
 - using the funding flexibilities which are now part of the Health Act 1999;
 - inspection and registration of long term facilities;
 - the strengthened role of the NHS Executive in determining the pattern of specialist hospital services;
 - the power of the national service frameworks and a national performance assessment framework in ensuring consistency of service quality;
 - the roles of the new organisations, the National Institute for Clinical Excellence and the Commission for Health Improvement;
 - business planning arrangements including Health Improvement Programmes and long term service agreements.

2. The impact of the problem

- 2.1 Information about the impact of the problem has been grouped for the purposes of this document under the following headings:
 - impact on the individual and their family;
 - prevalence of incontinence;
 - groups of people with particular needs;
 - current problems of service delivery.

Impact on the individual

- 2.2 Faecal and urinary incontinence is distressing, unpleasant and frequently socially disruptive. As a health issue incontinence can:
 - cause skin breakdown which may lead to pressure sores;
 - be indicative of other problems in children, such as emotional problems rather than physical disorders.

As a social issue, failure to manage faecal and urinary incontinence can:

- lead to bullying of children at school, adults in the workplace and older people in residential care and nursing homes;
- in children, cause emotional and behavioural problems;
- restrict employment, educational and leisure opportunities;
- lead to social embarrassment and social exclusion;
- result in people moving to residential and nursing homes incontinence is second only to dementia as an initiating factor for such moves;
- cause conflict between the individual and their carer;
- cause soiling and ruin clothes and bedding, leading to extra laundry costs and increased expense for these items.

For carers, incontinence is sometimes the last straw and is often a major reason for the breakdown of the caring relationship which can lead to admission to residential or nursing home care.

Prevalence of incontinence

- 2.3 It is difficult to measure the prevalence of incontinence accurately because:
 - the definitions of different degrees of incontinence are in part subjective;
 - people under-report the problem because of the associated embarrassment.
- 2.4 For the purposes of this guidance, incontinence has been defined as the involuntary or inappropriate passing of urine and/or faeces that has an impact on social functioning or hygiene. It also includes nocturnal enuresis (bedwetting).
- 2.5 There have been many studies, using varying methodologies, to estimate the prevalence of urinary incontinence in different populations. Currently the best information suggests that the prevalence is:

For people living at home:

- between 1 in 20 and 1 in 14 women aged 15-44;
- between 1 in13 and 1 in 7 women aged 45-64;
- between 1 in 10 and 1 in 5 women aged 65 and over;
- over 1 in 33 men aged 15-64;
- between 1 in 14 and 1 in 10 men aged 65 and over.

For people (both sexes) living in institutions:

- 1 in 3 in residential homes
- nearly 2 in every 3 in nursing homes
- 1/2 to 2/3 in wards for elderly and elderly mentally infirm
- 2.6 Information about faecal incontinence is not so extensive but best estimates suggest that the prevalence in adults at home is about 1% with 17% of the very elderly reporting symptoms. In institutional care the prevalence of regular faecal incontinence is about 25%.
- 2.7 It is estimated that about 500,000 children in the UK suffer from nocturnal enuresis (persistent bed-wetting). The prevalence decreases with age as follows:
 - one in six of children aged five;
 - one in seven of children aged seven;
 - one in 11 of children aged nine;
 - one in 50 of teenagers.

- 2.8 Faecal incontinence in children is also common with best estimates suggesting prevalence rates as follows:
 - one in 30 of children aged four to five;
 - one in 50 of children aged five to six;
 - one in 75 of children aged seven to ten;
 - one in 100 of children aged 11 to 12.

Special groups

- 2.9 Although incontinence mainly affects older people and women there are also a number of discrete groups for whom continence problems and access to services may pose problems. The following groups are more likely to encounter problems with incontinence or have access difficulties:
 - people with long term physical disabilities, neurological conditions and learning disabilities;
 - prisoners, asylum seekers and refugees;
 - homeless people and those living in hostels;
 - older people in residential care and nursing homes.
- 2.10 To ensure fair access to services health commissioners and providers should take particular note of difficulty in accessing health services for:
 - ethnic minority communities;
 - children in foster care and at boarding schools; and
 - travelling people.

Current problems in service delivery

- 2.11 The review of continence services has recognised a number of problems across the country which affect access to and delivery of continence services. Foremost among these are:
 - identification. Many incontinent people are likely to be in contact with health and social services but these services are not always aware of their problem;
 - lack of involvement of users at all levels of service planning and delivery;
 - geographical variations in people's eligibility to receive NHS services, particularly those not resident in their own homes;
 - geographical variations in the range and quantities of treatment provided and the time spent waiting;
 - geographical variations in the numbers of staff trained and the quality of the education and training given.

These issues can be tackled through the clinical governance agenda.

- 2.12 A particular concern has been the gross difference in NHS Trust policies for the provision of continence supplies. In 1997 Incontact commissioned a survey of 173 trusts which found that:
 - many NHS trusts were using arbitrary rules and policies to limit the supply of continence aids, rather than conduct individual assessments of need;
 - there were inflexible rules around the provision of either washable or disposable pads. About two
 thirds of NHS trusts were providing washable body worn pads, disposable bed pads and washable
 bed pads.
- 2.13 There was an unacceptable variation between trusts in the limits on the number of pads supplied in each delivery cycle. Exhibit 1 shows the number of pads allowed per 24 hours by NHS region and trust. The most common maximum pad allowance was five (47 trusts), the lowest two (one trust) and the highest seven (one trust).

Exhibit 1: Number of pads allowed per 24 hours analysed by NHS trust and region

NHS Region	Number of pads allowed per 24 hours by Trust providing this information					Total	Not Stated	Total	
	2	3	4	5	6	7			
Anglia & Oxford			2	6	2		10	4	14
North Thames		3	1	5	1		10	12	22
North West	1	1	4	5			11	9	20
Northern & Yorkshire		1	6	4	1		12	11	23
South & West		5	5	2			12	7	19
South Thames			2	12	1		15	7	22
Trent			1	2			3	6	9
West Midlands		1	6	3			10	4	14
Northern Ireland				1			1	8	9
Scotland				5	3		8	5	13
Wales			1	2		1	4	4	8
Total	1	11	28	47	8	1	96	77	173

3. Continence services

- 3.1 This Section contains expert opinion as to the best practice that the Group was able to identify, combined with research evidence where it was available. Proposals about continence services have been grouped as:
 - principles for service commissioning;
 - components of service delivery;
 - approaches to service organisation;
 - tools to improve service provision.

Principles

- 3.2 The Group considers that properly integrated continence 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;
 - 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.

Service components

- 3.3 Continence services are made up of a number of components, the most important of which are:
 - raising awareness among the public and health professionals;
 - identifying incontinent individuals;

- for each individual, conducting an initial assessment, agreeing a management/treatment plan and instigating initial treatment;
- reviewing treatment;
- supplying continence aids including pads, when indicated;
- advising and helping carers;
- providing specialist services in community and hospital settings.

Approaches to organisation – integrated continence services

- 3.4 Continence services provided for a specific population should be organised as **integrated continence services**. The various professionals providing care at different levels will be employed by different bodies but if services are to be integrated, in line with clinical governance principles, they should all:
 - work to common evidence based policies, procedures, guidelines and targets;
 - use agreed evidence based policies, procedures and guidelines;
 - undertake group audit and review.
- 3.5 Integrated continence services will include:
 - those involving the identification, initial assessment and care of people with incontinence provided by:
 - primary care and community staff;
 - staff in nursing homes and residential care homes;
 - hospital nurses.
 - a locally provided continence service comprising:
 - director of continence services;
 - continence nurse specialists including paediatric continence nurse specialists and specialist continence physiotherapists;
 - designated medical and surgical specialists;
 - investigation and treatment facilities.
 - national or regional units for specialist surgery.
- 3.6 Continence problems will usually **present and be identified** in a primary care setting but it is important to note:
 - many older people will live in continuing or long stay accommodation and they should have the same access to services as those living in their own homes;

- some people will present or by identified for the first time during a hospital admission and hospital nurses must be trained to carry out the initial management;
- carers receiving help because they are finding their caring relationships stressful and tiring may reveal that incontinence is a major cause of concern to them.
- 3.7 Each **primary care and community team** should have available professionals trained to carry out initial assessments and care, and arrangements that ensure that patients are identified, assessed and reviewed. There is no research evidence about the optimal way to provide a primary care continence service but three distinct approaches, have emerged:
 - creating posts which include the specific responsibility and a time provision for the delivery
 of continence services (continence co-ordinators) and giving them appropriate training;
 - providing a basic level of training to many members of a primary care team who provide continence services as part of their main job;
 - referring all patients with continence problems to a specialist continence service for initial assessment and treatment as well as more complex problems.
- 3.8 **Public education and awareness**. This is a critical factor in the delivery of good continence services. The early detection and treatment of incontinence requires recognition of signs and symptoms by all professional staff involved in patient care: doctors, nurses, physiotherapists and care workers. Detection is all the more difficult because patients may be embarrassed by their incontinence, and easily discouraged from discussing it. A proactive approach in clinical consultations (including consultations with carers) will assist with identification of cases as will the availability of information in GP surgeries and hospital clinics.

Assessment

- 3.9 All patients presenting with incontinence should be offered an **initial assessment** by a suitably trained individual. This assessment is in addition to the usual general patient assessment in respect of mental health, mobility and underlying conditions and might not be conducted at a single consultation. The key components of an initial continence assessment are:
 - review of symptoms and their effect on quality of life;
 - assessment of desire for treatment alternatives;
 - examination of abdomen for palpable mass or bladder retention;
 - examination of perineum to identify prolapse and excoriation and to assess pelvic floor contraction;
 - rectal examination to exclude faecal impaction (not to be carried out in children);
 - urinalysis to exclude infection;
 - assessment of manual dexterity;
 - assessment of the environment, eg accessibility of toilet facilities;

- use of an "Activities of daily living" diary;
- identification of conditions that may exacerbate incontinence, e.g. chronic cough.
- 3.10 A **management/treatment plan** should be discussed and agreed with every patient who has been assessed, and a copy should be given to the patient.
- 3.11 **Initial treatment** should be carried out in a primary care setting and can include:
 - general advice to patients and their carers about healthy living, in particular diet and drinking appropriate fluids;
 - implementation of bladder and bowel training regimens;
 - bladder training/timed voiding/prompted voiding for urge incontinence;
 - improving quality and access to toilet facilities and improving mobility, particularly in residential care, continuing care settings, schools and public places;
 - pelvic floor exercises particularly for women, during and after pregnancy, to prevent or cure urinary stress incontinence, for patients with urge incontinence and for men with post prostatectomy problems;
 - pelvic floor and anal sphincter exercises, to improve faecal continence;
 - provision of pads, continence aids such as enuresis alarms, and other supplies;
 - reviewing existing medication as some drugs may precipitate or exacerbate incontinence
 e.g. diuretics, analgesics;
 - management of faecal impaction;
 - medication such as:
 - anticholinergic drugs which may lessen bladder overactivity, detrusor instability;
 - anti-diuretic hormone for nocturnal enuresis which acts by temporarily reducing the formation of urine.

All patients should have a periodic review of their initial assessment to monitor the effectiveness of their treatment/management plan and to ensure there is adequate clinical improvement.

- 3.12 There is an unacceptable variation amongst NHS Trusts in the type, quality and quantity of **continence supplies** made available to patients. Section 2.12 gives the results of an Incontact survey. They are an essential component of the management of incontinence that should normally only be issued after an initial assessment or when a management plan has been completed and reviewed. Offering pads prematurely can lead to psychological dependence upon them, and reluctance to attempt curative treatment. Model principles for continence supplies are included in Annex 2. The key principles are:
 - pads only issued after an initial assessment;
 - full range of products available;

- supply of products should only be governed by clinical need;
- needs are regularly reviewed.
- 3.13 Residents of each health authority should have access to **integrated continence services**, managed by a **director of continence services** who would usually be a specialist continence nurse or physiotherapist responsible for:
 - overseeing and co-ordinating the development and implementation of common policies, procedures and protocols;
 - developing and maintaining care pathways to and from primary care and specialist services;
 - ensuring users and carers are involved in all aspects of the service;
 - ensuring services are made available to all the residents in the area served;
 - working closely with other services such as social services, education services and psychological services;
 - ensuring services are made available to all patients in hospital who require them;
 - co-ordinating educational activities for continence specialists, primary health care teams and others involved in the delivery of health and social care;
 - organising service-wide review, audit and research activities particularly to ensure national targets are met:
 - promoting awareness of incontinence.

3.14 As part of the specialist services there will be **continence nurse specialists and specialist continence physiotherapists** who should:

- deliver individual's continence care:
- maintain clinical competence and expertise by seeing referrals of the more complex cases from the primary care team and by direct referrals;
- play a key role in ensuring that the public and relevant organisations are aware of the importance of continence issues;
- have the main responsibility for ensuring that members of the primary care team are appropriately trained and professionally supported;
- have management responsibilities, particularly with respect to the provision of continence supplies including pads and aids;
- facilitate clinical audit;
- be involved in research and development in collaboration with colleagues;
- initiate local continence awareness activities, in liaison as appropriate with relevant national organisations.

3.15 Integrated continence services will, include designated medical and surgical specialists and investigation and treatment facilities such as:

- diagnostic facilities such as urodynamics including cystometry;
- facilities for all aspects of continence management provided by:
 - urologist or gynaecologist;
 - physician for older people;
 - paediatrician.
- 3.16 All services should have access to **specialist services**. These may be provided in the same locality as the treatment facilities or have clear referral paths to other hospitals. Specialist services include:
 - diagnostic services such as urodynamics including cystometry and anal ultrasound;
 - therapies such as patient specific pelvic floor muscle exercises, biofeedback, electrotherapy and bladder retraining;
 - surgery for urinary incontinence such as colposuspension and for faecal incontinence such as anterior repairs of anal sphincter;
 - medical specialties, eg coloproctology, neurology.
- 3.17. Local services should have specific referral arrangements with **national or regional**, **or sub-regional specialist units** which would provide:
 - sophisticated investigation facilities, particularly for faecal incontinence;
 - specialist services, eg artificial urinary sphincters.
- 3.18 Arrangements for the following operations could be reviewed:
 - secondary anterior repair of anal sphincter;
 - repair of anus with implantation of prosthesis;
 - new and innovative techniques such as sling procedures and urethral bulking agents for stress urinary incontinence until they have been evaluated by the Safety and Efficacy Register of New International Procedures (SERNIP);
 - augmentation cystoplasty, detrusor myectomy, neuromodulation and sacral anterior nerve root stimulation for urge incontinence;
 - urinary diversion for intractable incontinence;
 - implant of artificial urinary sphincter.
- 3.19 Evidence from other fields is accumulating to suggest that the best outcomes for **specialist surgery** are achieved when surgical teams operate on a critical volume of cases to maintain and improve their expertise.

Good practice in continence services

A review of operations for incontinence and where they were carried out was commissioned by the Group but the incompleteness of the national data meant few conclusions could be drawn. However, many NHS Trusts seemed to be carrying out small numbers of complex operations.

3.20 As effective operations, such as the implant of urinary artificial sphincters and the anterior repair of the anal sphincter, become available it is essential that they are only carried out in centres where surgeons carry out an adequate volume to maintain their expertise and achieve good outcomes for their patients.

Management tools

- 3.21 Tools which have proved to be useful in improving the delivery of continence services are:
 - care pathways;
 - audit packages, examples of which are shown in Annex 3;
 - performance indicators, examples of which are shown in Annex 3.
- 3.22 Performance indicators are statistical measures which should only be used to identify aspects of activity and circumstances which merit further study. They are not designed to provide definitive judgements about whether services are good or bad.
- 3.23 To underpin the guidance a number of local targets are suggested that could be used to develop local services. Each target includes:
 - the rationale for recommending the target;
 - a summary of effective interventions associated with the target;
 - service models to implement the target;
 - steps against which to assess progress mechanisms by which progress can be monitored.

4. Primary health care and community teams

Targets

- 4.1 For the population for which they are responsible, primary care and community teams together with general practitioners should aim to:
 - identify all people with incontinence;
 - offer them an appropriate assessment;
 - help carers to understand the condition and treatment (subject to the patient's consent);
 - deliver first-line treatments;
 - facilitate access to specialist services.

Rationale

- 4.2 Key points supporting the introduction of these targets are:
 - incontinence is so common that its initial management is best carried out by primary care and community professionals;
 - professionals have to actively question patients and carers about symptoms because patients may be unwilling to admit they have an embarrassing condition;
 - even simple initial treatments should not be started without an assessment.

Effective interventions

- 4.3 Effective interventions related to these targets are:
 - initial assessment by a suitably trained health professional as specified in paragraph 3.9;
 - initial treatments listed in paragraph 3.11, in particular:
 - pelvic floor exercise training especially for pregnant women and women with stress incontinence;
 - bladder training;
 - anti-diuretic hormone for nocturnal enuresis;
 - anti-cholinergic medication for urge incontinence.

Service models

- 4.4 If primary care professionals are to provide the initial management and treatment of patients with incontinence it is essential that a systematic approach is adopted. Systems of care should be implemented to ensure that:
 - primary care and community professionals are identified and trained to carry out the tasks;
 - pro-active questioning about symptoms is done for particular groups at risk such as:
 - pregnant women and women in the six months post-delivery;
 - older people and their carers;
 - people with disabilities;
 - school age children;
 - menopausal women.
 - each practice uses care pathways agreed with the local Continence Director;
 - a record is made of:
 - the presence and severity of symptoms;
 - whether an assessment has been carried out;
 - whether a management plan has been prepared;
 - basic treatment and management provided.

Steps

- 4.5 The implementation of these continence service targets will provide primary care and community teams with a mechanism for the continual improvement of care for this group of patients. The steps listed below provide a measure against which every practice can assess itself and they should be reflected in health improvement programmes/long term service agreements:
 - step 1, the primary care and community team has a systematic approach to managing continence
 problems involving pro-active questioning (including carers), assessments by trained personnel,
 management plans and the recording of requisite data;
 - step 2, the primary care and community team regularly reviews continence provision;
 - step 3, the primary care and community team meets performance targets laid down in the relevant health improvement programme.

Monitoring

4.6 The Performance Assessment Framework (PAF) will be used to assess the overall performance of the NHS both nationally and locally. Indicators related to these targets could include a clinical audit by each practice of individual cases, the results of which are available to others, such as researchers and voluntary organisations and can demonstrate progress.

5. Targets for health authorities, primary care groups and primary care trusts

Targets

- 5.1 Health Authorities (HA) and their associated Primary Care Groups (PCG) or Primary Care Trusts should ensure that:
 - their residents have access to integrated continence services which includes access to investigative facilities and specialist surgical services;
 - information collected is compatible with that collected by primary care and community teams.

Rationale

- 5.2 Key points supporting the introduction of these targets are the need for:
 - a collaborative approach between health authorities, primary care groups, primary care trusts and local authorities in commissioning services;
 - common policies, procedures, guidelines and standards used by all the professionals providing care to the resident population;
 - easy access for those patients who require it to the relevant specialist care;
 - training and support for the primary care team.

Effective interventions

- 5.3 Effective interventions related to these targets are:
 - arrangements to integrate continence services, providing local specialist facilities and supporting staff in the primary care team (see section 3.13);
 - arrangements for training primary care staff (see section 9).

Service models

5.4 The systems of care that might be adopted are discussed in section 3.

Service review

5.5 Health Authorities and their associated primary care groups should be able to compare their performance over time and with other Health Authorities.

Indicators related to training and continuous support include:

- users and carers experience of services;
- hours of continence training provided to staff per 100,000 HA/PCG population;
- number of whole time equivalent (WTE) of continence specialist nurse and specialist continence physiotherapists per 100,000 HA/PCG population.
- 5.6 Indicators related to access to specialist facilities include (per 100,000 HA population):
 - rate of referral to a specialist from general practice;
 - rate of cystometry;
 - the rate of coloposuspension for stress incontinence.
- 5.7 Many of these indicators were considered by the Working Group on Outcome Indicators for Urinary Incontinence and further details are included in Annex 3.

Step

- 5. 8 Implementing these continence service targets will provide health authorities and their associated PCGs/PCTs with a mechanism for reviewing the continual improvement of care for this group of patients. The steps listed below provide a measure against which they can assess themselves.
 - step 1, health authority and PCGs/PCTs have commissioned integrated continence services which
 include arrangements for the specialist services;
 - step 2, health authority and PCGs/PCTs regularly review their performance in this area.

Monitoring

- 5.9 The Performance Assessment Framework (PAF) will be used to assess the overall performance of the NHS both nationally and locally. Measures relevant to these targets could include:
 - number of WTEs of specialist continence physiotherapists/continence nurse specialists for urinary and faecal incontinence which would relate to the PAF criteria for access;
 - an audit of services, building on the individual practice audits, the results of which are available to others, such as researchers and voluntary organisations and can demonstrate progress.

The PAF includes as a composite indicator for the effective delivery of healthcare, admission rates for kidney/urinary tract infections. The indicator provides a measure of potentially "avoidable hospitalisations" as a result of conditions, which should, at least in part, be treatable in primary care.

6. Joint targets for health and local authorities: children

Targets

6.1 Health and local authorities should put in place arrangements that ensure children are not excluded from normal pre-school and school educational activities, solely because they are incontinent.

Rationale

- 6.2 Enuresis is very common and incontinence fairly common amongst pre-school children and at school entry. "Normal" child development involves the gradual acquisition of faecal and urinary continence. The rate at which children develop bladder and bowel control varies and is influenced by cognitive ability and various family and socio-cultural factors. Although being late coming out of nappies is by no means necessarily associated with cognitive difficulties, it is likely that children with global developmental delay will be particularly late in this respect.
- 6.3 The children with a mild to moderate degree of global delay will probably not have a statement of special educational needs by the time they start at nursery school. This reflects variously that:
 - the child may be on an assessment place;
 - the full extent of their difficulties may not become apparent until they are seen alongside their peers;
 - such delays are often familial and coupled with social disadvantage which tends to militate against getting an early statement.
- 6.4 The two main other groups of children with continence difficulties are children who have a physical condition which hinders continence and children who have developed secondary enuresis or encopresis as a behavioural response to emotional difficulties. There can be overlap between these conditions (and indeed with globally delayed development). Of the children with physical difficulties underlying their incontinence, those with neurological problems are likely to have been identified pre-school and may well have a statement of SEN. Those with secondary incontinence associated with mental health problems are quite likely to be assessed in line with the Code of Practice as incontinence will probably not be the only behavioural problem they have.

This means that:

- School and pre-school institutions should, wherever possible, be able to care effectively for children with these conditions;
- children should not be excluded from normal educational activities solely because of a manageable condition.

Effective interventions

- 6.5 Effective interventions related to the target are:
 - early assessment by a suitably trained health individual, in consultation with parents and other carers including school staff. Where a child has incontinence associated with developmental and/or emotional difficulties, they may need a statutory assessment in line with the DFEE Code of Practice on identification and assessment of special educational need. If the child is considered to require provision beyond that which could reasonably be expected in mainstream school, any additional provision (see below) would be set in a statement of special educational need;
 - each assessment, to specify the type of incontinence, a clear treatment and/or management strategy, any additional resources or adaptations, a named person responsible for the treatment implementation, coordination with other agencies, six monthly reviews and staff training;
 - recognise the need for unrestricted access to non-threatening toilet facilities, including one extended cubicle with wash-basin per school for children with disabilities, children who need to self-catheterise etc. If these facilities are normally locked, children should have the toilet key, rather than need to ask for it. (See the guidance on School Premises Regulations from DFEE for further guidance);
 - availability of accessible, clean, fresh-water drinking facilities.

Service models

- 6.6 If children with incontinence are to attend normal educational activities, systems of care should be implemented that:
 - preserve the dignity and independence of the child or young person and avoids the risk of ridicule or bullying from peers or staff;
 - carry out the continence treatment or management plan as agreed in the assessment;
 - enable good pathways of communication from child or young person to the school-based carer, the multi-disciplinary team and the parent or carer;
 - provide adequately trained school-based care staff.

Clinical audit

6.7 Educational establishments should record any child who was excluded from normal education solely because of enuresis or incontinence.

Monitoring

6.8 Should be undertaken in accordance with ERIC's current minimum standard guidelines for children with enuresis which will be extended to include children with incontinence.

7. Joint targets for health and local authorities: residential care and nursing homes

Targets

Health and local authorities should put in place arrangements that ensure people with incontinence, who require residential or domiciliary care are identified, assessed and appropriately managed and treated.

Rationale

- 7.2 Key points supporting the introduction of the targets are:
 - incontinence is very common among residents in long stay facilities (see section 2.5);
 - surveys suggest that there is considerable variation in the management of incontinence in such facilities;
 - homes which state they are able to provide services for people with incontinence should be able to demonstrate this.

Effective interventions

- 7.3 Effective interventions related to the target regarding homes are:
 - Easy access to toilet facilities;
 - initial assessment by a suitably trained individual as specified previously in paragraph 3.9;
 - initial treatments listed in paragraph 3.11, in particular:
 - implementation of bladder training regimes;
 - improving access to toilet facilities;
 - management of faecal impaction;
 - provision of continence supplies;
 - appropriate use of indwelling catheters.

Service models

- 7.4 If people in residential and nursing homes are to receive proper treatment for their incontinence there must be a systematic approach to identifying and assessing the problem. Systems of care should be implemented that ensure:
 - each home has staff trained to identify and assess incontinent patients;
 - each home uses care pathways agreed with local continence service director;
 - every effort is made to facilitate access to toilet facilities;
 - a record is made of:
 - the presence and severity of symptoms;
 - whether an assessment has been carried out:
 - whether a management plan has been prepared;
 - basic treatment and management provided;
 - treatment outcome.

Clinical audit

- 7.5 All nursing and residential homes should be invited to participate in an annual clinical audit which allows them to compare their performance over time and with other similar homes.
- 7.6 Indicators related to this target should include:
 - the prevalence of incontinence in the home;
 - the rate of clinical assessment in the home;
 - the rate of use of indwelling catheters;
 - views of residents, family and friends;
 - links the home has with statutory organisations on education and training issues.
- 7.7 Many of these indicators were considered by the Working Group on Outcome Indicators for Urinary Incontinence and further details are included in Annex 3, as are the results of an audit carried out in homes by the Royal College of Physicians.

Steps

- 7.8 The implementation of the continence service targets related to homes will provide health and local authorities with a mechanism for the continual improvement of care of people in nursing and residential homes. The steps listed below provide a measure against which every home can be assessed and they should be reflected in health improvement programmes and long term service agreements:
 - step 1, the home provides a systematic approach to managing continence problems involving assessments by trained staff, management plans and the recording of requisite data;
 - step 2, the home has data no more than 12 months old that describe all the items suggested as performance indicators;
 - step 3, the home meets performance targets laid down in the relevant health improvement programme/long term service agreements.

Monitoring

7.9 The Performance Assessment Framework (PAF) will be used to assess the overall performance of the NHS, locally and nationally. "Fit for the future" suggests national standards of care in nursing homes.

8. Targets for in-patient care

Targets

- 8.1 NHS trusts should ensure that:
 - effective surgical procedures for incontinence are undertaken and that they are carried out by surgeons who do an adequate volume to maintain their expertise and achieve good outcomes for their patients;
 - patients, newly presenting in hospital with incontinence, are properly assessed and managed;
 - patients in NHS continuing care facilities with incontinence are identified, assessed and appropriately managed and treated;
 - proactive steps are taken to identify patients with incontinence problems that might arise after treatment.

Rationale

- 8.2 Key points supporting the introduction of these targets are:
 - increasing evidence that the best surgical results are achieved by teams who do an adequate volume of operations;
 - accumulating evidence that some operations for incontinence are better or worse than others;
 - the importance of regularly reviewing the results of surgery;
 - that patients presenting with incontinence in hospital are frequently poorly managed by inexperienced staff;
 - the high prevalence of incontinence in NHS continuing care facilities;
 - evidence from surveys that there is considerable variation in the quality of continence services provided in NHS long stay facilities.

Effective interventions for in-patients who are admitted to hospital for continence treatment

- 8.3 Effective interventions related to surgery that should be available in most main hospitals are:
 - investigations before surgery (see paragraph 3.9);

- for urinary incontinence colposuspension, but not anterior vaginal repairs which lead to inferior outcomes;
- identification of obstetric 3rd degree tears of the perineum in association with child birth.

Service models

- 8.4 If surgical teams are to produce the best results, systems of care should be implemented that ensure:
 - all procedures are carried out by designated consultant teams;
 - patients are adequately investigated before operation;
 - records are made of key clinical details.

Clinical audit

- 8.5 Surgical teams as part of their clinical governance procedures should be involved in an annual clinical audit which allows them to compare their performance over time and with other surgical teams.
- 8.6 Indicators for urinary incontinence related to this standard are:
 - rate of pre-operative cystometry in women undergoing surgery for stress incontinence;
 - rate of emergency re-admission for a urinary related condition or a specific complication within 30 days of surgery;
 - rate of re-operation within two years of operation;
 - % of anterior repairs undertaken in women with stress incontinence without vaginal prolapse.
- 8.7 Indicators for faecal incontinence related to this standard are:
 - rate of pre-operative anal ultrasound and ano-physiology for patients undergoing operations for faecal incontinence;
 - rate of emergency re-admission for specific complications within 30 days;
 - rate of re-operation within two years of operation.

Patients who have a continence problems in hospital

- 8.8 Effective interventions related to managing newly diagnosed patients are similar to those used by the primary care team:
 - initial assessment by a trained individual as specified in paragraph 3.9;
 - initial treatments as listed in paragraph 3.11.

Service models

- 8.9 To manage newly diagnosed patients effectively:
 - staff have to be adequately trained (see section 9);
 - pro-active questioning of patient groups at risk should be instituted;
 - care pathways which have been agreed with local continence director should be used;
 - appropriate records should be made;
 - discharge plans include a continence management plan, which should be shared with the patient and carer (once patients have consented to this).

People with continence problems in NHS continuing care facilities

- 8.10 Effective treatments related to NHS continuing care, particularly older people are similar to those for residential and nursing homes:
 - initial assessment by a trained individual as specified in paragraph 3.9;
 - initial treatments as listed in paragraph 3.11, in particular:
 - implementation of bladder training regimes
 - improved access to toilet facilities
 - review medication
 - management of faecal impaction
 - provision of continence supplies
 - appropriate use of indwelling catheters.

Service models

- 8.11 In continuing care facilities:
 - staff have to be trained to identify and assess incontinence (see section 9);
 - care pathways which have been agreed with local continence specialists should be used;
 - every effort should be made to make access to toilets easy;
 - appropriate records should be made;
 - progress should be regularly reviewed.

Clinical audit

- 8.12 For continuing care facilities an annual clinical audit should be done allowing Trusts to compare their performance over time and with other similar units.
- 8.13 Indicators related to this standard should include:
 - prevalence of incontinence in the unit;
 - rate of clinical assessment in the unit;
 - rate of use of indwelling catheters;
 - quality of life indicators for individuals.
- 8.14 Many of these indicators were considered by the Working Group on Outcome Indicators for Urinary Incontinence and further details are included in Annex 3.

Steps

- 8.15 The implementation of these continence service targets provide trusts with a mechanism for the continual improvement of care for incontinent patients. The steps listed below provide a measure against which every trust can assess itself and they should be reflected in health improvement programmes:
 - step 1, the trust has a systematic approach to managing continence problems with respect to patients having continence surgery, newly diagnosed patients and those in continuing care facilities;
 - step 2, the trust has clinical audit data no more than 12 months old that describes all the items prescribed as performance indicators;
 - step 3, the trust meets performance targets laid down in the relevant health improvement programme.

Monitoring

8.16 The Performance Assessment Framework (PAF) will be used to assess the overall performance of the NHS, nationally and locally. A measure relating to the surgical standard is the rate of emergency re-admission within 30 days of surgery and the percentage of anterior repairs undertaken in a population of women having surgery for stress incontinence without prolapse.

9. Implementation

- 9.1 In order to develop continence services for their local population, Health Authorities need to ensure that integrated continence services which cover prevention, assessment, treatment and specialist care, are routinely available. These services need to be underpinned by access to appropriate training for nursing and medical professionals and physiotherapists. To implement this guidance, health authorities, with users, Primary Care Groups, Primary Care Trusts, NHS Trusts and other local agencies such as social services and the independent sector, should review the provision of continence services for adults and children and develop a strategic plan so that:
 - primary care and community teams are providing initial assessment and frontline treatment;
 - there are integrated continence services in place;
 - there are robust care pathways for patients;
 - all sectors of continence care can monitor their performance;
 - the targets outlined in the guidance are being met;
 - that appropriate training is identified and accessed.
- 9.2 This action should be undertaken as part of the programme to develop Health Improvement Programmes, long term service agreements and clinical governance.

Training

9.3 Primary Care Groups /Primary Care Trusts and NHS Trusts should develop and deliver in-service programmes of education and training to reflect contemporary practice and in conjunction with Higher Education Institutes (HEIs) to ensure that the curricular content of pre-and post registration training reflects continence service policy. One way of achieving this might be through the development of more joint appointments between the NHS and Universities. These arrangements should be set in the context of partnerships with local education and training consortia to ensure that the education provided matches local needs and reflects the importance of shared learning. NHS Trusts should ensure that there are planned programmes of education and training, commissioned by Consortia and in conjunction with HEIs to support staff assessing and treating patients with incontinence, which should form part of an individuals planned programme of Continuing Professional Development.

Monitoring

- 9.4 There are a number of measures that are already in place or will be introduced over the coming year that relate to continence services. These include:
 - the Performance Assessment Framework, a composite indicator for the effective delivery of healthcare admission rates for kidney/urinary tract infections as an indicator of effective primary care;
 - the National Service Framework for older people, when published;
 - the Commission for Care Standards;
 - the health outcomes indicators report "Urinary incontinence" and the development of clinical indicators.

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Continence product supplies

Introduction

- 1. Continence products should not be supplied before an initial continence assessment, which should be carried out without delay. Products may be needed temporarily by patients awaiting or undergoing treatment and by those whose incontinence has proved intractable to treatment. Incontinence pads have sometimes been perceived as a quick fix in the past, leading to misuse and overuse.
- 2. It is important to consider cost-effectiveness and quality of life rather than just product costs. A focus on costs alone is likely to be unsatisfactory for patients, is not conducive to treatment and will discourage companies from being creative and innovative in developing better products.
- 3. There is a very wide variety of products that include: pads, sheaths, catheters and urinals, often making it very difficult for health professionals to stay aware of all the options and to make cost effective choices in purchasing.
- 4. The initial assessment of a person's continence needs at primary care level should include assessment of the need for appropriate continence products.

Incontinence Pads (disposable and reusable)

Assessment

Nobody should be issued with pads without an initial continence assessment. However, the
assessment should not be solely to determine which pad is most appropriate, but should include
all the elements of an initial assessment.

Type of Product

- There should be a range of pads available in all categories, including bed pads, a variety of sizes/absorbencies of body-worn pads with pants, and all-in-one products for special cases.
- Consideration should to be given to patient choice.

Supply of Products

- For some frail individuals pads may be chosen, after assessment, as the most appropriate initial management option.
- There should be periodic re-assessment (at least yearly) of those receiving long-term supplies to check that needs have not changed, and that there is not a newer product available, which would be more suitable.

- Provision of pads should be available equally to anyone in the geographical area, regardless of where they live (e.g. own home, or residential home). Special considerations apply to the needs of people who are homeless, in prison or live in other settings. Provision also needs to be made for people who reside temporarily in another area for part of the year (e.g. university students).
- In most cases it will not be appropriate to provide free pads before the age of four, but flexibility should be allowed for special cases such as children with multiple handicaps and decisions should be made in liaison with the designated Paediatrician.
- Pads should be provided in quantities appropriate to the individual's continence needs. Arbitrary
 ceilings are inappropriate. Guidelines should be developed for the Primary Health Care Team to
 aid product choice, but these should not be seen as rules.
- A few patients, such as those with copious diarrhoea, a bladder or bowel fistula and some people with learning difficulties have needs well above the average and will need large quantities of pads to provide adequate containment. It is not acceptable for people with faecal incontinence to be supplied with so few pads that they have to reuse the same pad after they have become soiled, as serious skin complications can develop.
- It is unacceptable to have waiting lists for pads as a means of rationing the service.
- NHS services, which includes continence pads, under Section 1 of the NHS Act 1997, must be free of charge. (EL(91)129).
- Access to the service should not be de facto limited by the requirement to collect pads from a central point.

Reusable Pads

- Since reusable pads are not suitable for everyone (especially those with faecal incontinence and menstruating women) their availability should not be to the exclusion of disposable pads.
- Assessment for reusable products should include a check that adequate washing and drying facilities
 are available; that the user/carer can cope with the wash load; and that laundry costs are not
 prohibitive.
- In hospitals and nursing homes, sufficient products will be needed to ensure a continuous supply, taking into account laundry turn-round times and breaks in laundry service during holiday times.

Evaluation

- There should be a monitoring mechanism to ensure that the decision to use pads is appropriate and that potentially treatable conditions are not being missed. In many areas it will be appropriate for the continence specialist to take this monitoring role.
- The supply of disposable pads should be monitored using a computer database, so that information can be easily retrieved and analysed.

Environmental issues

There is increasing concern over the growing costs of disposing of single use pads and the pressures on land fill sites and incinerators. Reusable products have a "greener" image, but it has not been established that either category of product is environmentally superior to the other. Washing and drying reusables carry costs to the environment too.

Products available on Prescription (FP10)

Catheters, intermittent catheters, male appliances and sheath urinals and some skin care products are listed in the drug tariff and are prescribed on FP 10. This means that the same range of products is available to all patients, regardless of where they live. Nurses are usually involved in patient assessment and advice on the management of these products. Periodic review (at least annually) is recommended to ensure that prescriptions remain appropriate.

Products to preserve continence

- A better knowledge and understanding by health professionals is needed about products such as handheld urinals (especially female urinals) and lifestyle aids and adaptations such as commodes or raised toilet seats. These can often prevent the need for continence products.
- There should be clear protocols regarding the provision and distribution of these products.

Information issues

- 1. This Annex contains:
 - details of urinary incontinence outcome indicators recommended by a national group;
 - examples of audit packages developed by particular organisations and their use.

Health outcome indicators

- 2. In 1999 the NHSE published the Report of the Working Group on Outcome Indicators for Urinary Incontinence (UI). Using a variety of check lists, including a health care model, the Group identified and specified a set of indicators which could be used for a variety of purposes. The indicators were grouped according to the intervention aim they were associated with and ascribed an implementation priority as broadly:
 - able to be implemented now;
 - further development work required.
- 3. Indicators related to the **avoidance or reduction of risk of urinary incontinence** are:
 - incidence and prevalence of UI (further work);
 - prevalence of UI in long term care (implement);
 - incidence of UI among women after pregnancy (implement);
 - rate of pelvic floor exercise training among pregnant women (further work).
- 4. Indicators related to the avoidance or reduction of the adverse effects of delayed diagnosis and treatment are:
 - measurement of delay to presentation with UI (further work);
 - clinical assessment rates after presentation with UI to GP (implement);
 - rate of referral after presentation with UI (implement);
 - clinical assessment rates in long term care (implement).

- 5. Indicators related to **treating the underlying mechanisms and causes and to avoiding adverse consequences** are:
 - rate of pre-op cystometry in women having surgery for UI (implement);
 - rate of 'one to one' training in pelvic floor exercises among women with stress incontinence (further work);
 - percentage of anterior repairs undertaken in a population of women having surgery for stress incontinence without prolapse (implement);
 - rate of re-operation within two years of surgery for UI (implement);
 - rate of emergency re-admission for UI related condition or specific complication within 30 days of discharge in people who have had surgery for UI (implement);
 - changes in urinary symptoms from before treatment to six months after in people receiving treatment for UI (implement).
- 6. Indicators related to **reducing the impact of urinary incontinence on general well-being** are:
 - use of indwelling catheters in long term care (implement);
 - changes in health related quality of life assessed before and six months after treatment for UI (further work);
 - measure of patient satisfaction assessed six months after treatment for UI (further work);
 - measure of attainment of patient specified outcome goals after treatment for UI (further work).

Royal College of Physicians' audit packages

- 7. The Royal College Physicians' Research Unit has developed a number of packages to assist in auditing services, particularly those for old people. A general audit package for urinary and faecal incontinence was first developed in 1995 and the most recent version was completed in 1998. The CARE scheme, a generic clinical audit tool for the long term care of elderly persons was published initially in 1996, and after piloting, a revised package was produced in 1998.
- 8. Many of the indicators selected by the Outcome Indicators Working Group were from the College's audit packages. A survey was carried out by the College Research Unit in 1998 of 17 residential homes, 13 nursing units and six long stay wards to test the feasibility of producing three of the measures.

Key documents

- 1. **DoH (1991): Agenda for Action on Continence Services.** ML(91)1 *The last piece of guidance, still very relevant today.*
- 2. Continence Foundation (2000): Continence Resource Pack. Continence Foundation, London. This resource pack, now in its third edition, is intended particularly for use by those in primary care. It contains several useful leaflets, protocols and reference material.
- 3. Roe, BH., Addison, RR., Clayton, J. (1992): The Role of the continence Advisor. RCN, London. Report of consensus workshops held by RCN Continence Care Forum for UK. Mission statement and four principle functions of continence are identified and discussed.
- 4. Association for Continence Advice (1993): Guidelines for Continence Care. ACA, London. These guidelines are to indicate what clients should expect from health services, local authorities, employers and those offering public services in order to manage continence problems. They also aim to guide providers of services, raising awareness of the facilities required. These are clearly written and provide a useful guide to continence services provision, but direct guidelines for practice lack reference to supporting research.
- 5. **Barrett, JA. (1993): Faecal Incontinence and Related Problems in the Older Adult. Edward Arnold, London.** A useful textbook which specifically addresses faecal incontinence, including the physiological aspects and practical management of this condition. The book is based on recent research and is very well referenced.
- 6. **Butler, RJ., (1993): Enuresis Resource Pack. ERIC, Bristol.** This pack contains charts, questionnaires and information to assist health care professionals dealing with children with enuresis. The current (revised) edition came out in 1997.
- 7. Rhodes, P., Parker, G. (1993): The Role of Continence Advisors in England and Wales. SPRU. York. The report of a research study into the role of continence advisers. It provides useful information on the history and changing role of the continence advisor and considers implications for future continence services.
- 8. Royal College of Nursing (2000): Commissioning Continence Advisory Services: an RCN Guide. This useful guide, revised from an original 1997 version, concentrates on the role of the continence nurse specialist.
- 9. Brocklehurst, N. (1994): Purchasing for Continence Promotion, Guidelines for Health Authorities and GP fundholders on commissioning continence services. West Midland Regional Health Authority. A very useful booklet which is designed to help purchasers develop effective continence services. It is well written, referenced and provides examples of good practice.
- 10. Clarke et al. (1994): Nocturnal enuresis: a strategy for management. Hospital Update, September, Supplement. Produced in conjunction with Ferring Pharmaceuticals Ltd. This report of a working party provides protocols for clinical assessment and age-related management plans for nocturnal enuresis.
- 11. Roe, BH., Williams, K., (1994): Clinical Handbook for Continence Care. Scutari Press. This is a useful practical handbook with research based recommendations for clinical practice.

- 12. Charter for Continence (1995): Developed by the Continence Foundation, Incontact, ACA, RCN Continence Care Forum, ERIC, Spinal Injuries Association, and Multiple Sclerosis Society. Produced with an education grant from Bard Limited. This charter presents the specific needs and rights of people with bladder or bowel problems. It outlines the resources available and the standards of care that can be expected.
- 13. Continence Foundation (1995): Commissioning Comprehensive Continence Services: Guidance for Purchasers. Continence Foundation, London. This document is aimed at purchasers of continence services. It provides relevant and useful background information on the need for a continence service, requirements of such a service and contracting for this service.
- 14. **Haggar V (1995): Working with Ethnic Minority Communities:** *Nursing Standard* **9(25)** *Suppl:* **3–4.** *A useful, brief document outlining issues to consider when working with ethnic minority communities.*
- 15. ERIC (1995): Charter for Children with Bedwetting and Daytime Wetting and their Families. Enuresis Resource and Information Centre (ERIC), Bristol. This charter presents the specific needs and rights of children who experience bedwetting and daytime wetting and guidance for their families. It outlines the resources available and standards of care that can be expected.
- 16. NHSE (1995): Incontinence [Patients Perceptions of Services]. NHS Executive, Leeds. This booklet is part of a series aimed primarily at purchasers. It represents the views of users of continence services. It poses challenges to purchasers of services and is a useful reminder of the relevance of consumers' views.
- 17. RCP (1995): Incontinence: Causes, management and provision of services. Report of the Royal College of Physicians, London. Guidelines produced by a working party of the Royal College of Physicians.
- 18. Brocklehurst, J. (1998): Promoting Continence: Clinical Audit Scheme for the management of urinary and faecal incontinence. *Royal College of Physicians.*
- 19. AHCPR (1996): Urinary incontinence in Adults: Clinical Practice Guidelines. (Update) US Dept of Health and Human Sciences. Agency for Health Care Policy and Research, Rockville. This consensus guideline aims to improve reporting, diagnosis and treatment of UI; reduce variations in clinical practice; educate health professionals and consumers about the condition. It applies to UI acquired in adults and is not designed for children. Extraurethral incontinence is not addressed.
- 20. Clayton, J., Smith, K., Qureshi, H., Ferguson, B. (1996): Costs of Incontinence to Individuals and to Services, and User's Perceptions of quality and effectiveness of Services. Centre for Health Economics, Social Policy Research Unit. University of York. One of the latest attempts to cost incontinence. Some very interesting, important and telling information from the User's perspective.
- 21. Pearson, M., Richmond, D., Cullum, N. et al (1996): The Development of Methodologies to Identify Urinary Incontinence and set Targets for Health Gain. Health and Community Care Research Unit. University of Liverpool. This report makes 22 recommendations for healthgain relating to a variety of areas including purchasing, referral pathways and training.
- 22. Roe, B., Wilson, K., Doll, H., Brooks, P. (1996): An Evaluation of Health Interventions by Primary Health Care Teams and Continence Advisory Services on Patient Outcomes related to Incontinence. Health Service Research Unit. University of Oxford. An interesting piece of research commissioned by the Department of Health that looks at the difference in outcomes between an area with a continence service and one without.
- 23. Morgan, R. (1996): Guidelines on Minimum Standards of Practice in the Treatment of Enuresis. ERIC, Bristol. These guidelines are in the form of minimum standards for an enuresis service. Target standards are also given which enable the improvement of existing services. Referral, assessment, treatment and evaluation are covered.

There are few references to support recommendations for practice, but this document is a very useful guide for purchasers and providers to the service levels required.

- 24. Brocklehurst., J. et al. (1997): Working Group on Outcome Indicators for Urinary Incontinence. Unit of Health Care Epidemiology. University of Oxford. Commissioned by the Department of Health this report gives advice on indicators of the prevention, treatment, and management of incontinence and makes recommendation about the practicalities of the compilation and interpretation of the indicators.
- 25. First International Conference for the Prevention of Incontinence (1997): Consensus Statement. Continence Foundation, London. A statement of what is known about prevention, with suggestions for research, produced by 42 invited experts at a conference financed by an educational grant from Pharmacia & Upjohn.
- 26. Foulkes, S., Oliver, H., Rowley, P., White, M. (1997): Catheterisation in Schools: guidelines for good practice. A useful statement addressed to school doctors and nurses.
- 27. Health Services Accreditation Unit (1997): Standards for Continence Advisory Services. Health Services Accreditation, Battle, East Sussex. The HAS, created by ten health authorities in the south-east, has produced this useful specification and associated accreditation instruments which have been applied in many areas.
- 28. **Anthony, B. (1998): Provision of continence supplies by NHS Trusts. Middlesex University.** A report of a piece of research that was commissioned by Incontact the consumer organisation to look at the inequalities of pad provision around the country.
- 29. Button, D., Roe, B. et al (1998): Continence Promotion and Management by the Primary Health Care Team. Consensus Guidelines. Whurr Publishers Ltd. London. These guidelines represent the principles of good practice supported by evidence based rationales for the Primary Health Care Team. Developed as part of the NHS Executive Strategy for Major Clinical Guidelines.
- 30. Continence Foundation (2000): Continence Products Directory (fifth edition). Continence Foundation, London. This very useful resource provides a near comprehensive listing of products available for the management of incontinence with details including supplies and manufacturers.
- 31. Interprofessional Collaboration in Continence Care [ICCC] (1998): Nurses and Physiotherapists Working in Continence Care. Report of a Consensus Meeting held at the Kings Fund. Funded by an educational grant from Phamacia & Upjohn.
- 32. Audit Commission (1999): First Assessment: A Review of District Nursing Services in England and Wales. This report used incontinence as an indicator for care when reviewing the district nursing services.
- 33. Abrams P, Khoury S and Wein A (editors) (1999): *Incontinence, 1st International Consultation on Incontinence*. World Health Organisation and International Union Against Cancer, Plymbridge Distributors, Plymouth. The result of a consensus conference of invited experts, this brings together better than any other single document the current state-of-the-art knowledge of the subject.



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It is also on our website on: www.doh.gov.uk/continenceservices.htm