Committee 13

Promotion, Education and Organization for Continence Care

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I. INTRODUCTION

Urinary incontinence (UI) is a most common problem, affecting over 200 million people worldwide. UI seriously affects both sufferers and caregivers and leads to major deterioration in quality of life (QOL). It is surrounded by taboos, misinformation and ignorance. Most sufferers fail to seek help despite safe and effective treatments that are available.

The chapters in this volume have outlined the tremendous advances over the past two decades in the understanding of the causes of UI, and in the ability to diagnose and treat those patients who present for help. However, this is of limited usefulness if:

1) The majority of incontinent people remain unaware and too embarrassed to seek professional help;

2) Health care professionals who provide primary care services are often unaware of the improvement in health status resulting from the active detection of UI.

3) Health care professionals' attitudes towards incontinence in general is faulty due to lack of basic knowledge of the effect of incontinence on QOL, on mental, social and economical aspects.

4) Many health care professionals generally lack basic knowledge in this field and are unaware of recent advances;

5) Those who provide specialist services are unaware of, or fail to liaise with, the services provided in primary care

6) Those responsible for funding health care often do not pay for continence services.

The Committee on *Promotion, Education and Organization for Continence Care* had a challenge, as there is little evidence available on these issues. Countries throughout the world continue to be at various stages of addressing the challenges posed by the following questions.

1) Given the millions of incontinent people worldwide, how can the message that help is possible be communicated?

2) And how can this be done in the best interests of patients?

3) How can countries without any current service for incontinent people most effectively initiate development of those services?

UI is such a common problem that in most healthcare systems it is unrealistic, and probably undesirable, to expect that every incontinent person will have access to a specialist center and a thorough evaluation as a first option. Indeed, for countries with less developed health services, treatment of UI will not be a priority compared to more basic services. It is only as countries become more affluent that the relative luxury of continence services can be afforded. In countries with existing services, these have largely grown up on an *ad hoc* basis with little coordinated planning. In most countries, the structure of the medical services payment system has directed access to UI evaluation and treatments, making direct comparisons difficult [1]. As other countries develop services, they will have the opportunity to consider the most efficient and effective use of scarce resources, and hopefully learn from what has happened elsewhere.

There is likely to be a shift in what is needed and what is affordable over time. For example, in the past maternal and infant mortality eclipsed all other issues surrounding pregnancy. In the developed world, incontinence and pelvic floor dysfunction are now being addressed as an issue in childbirth. Increasing the use of incontinence services will require a change in public and professional knowledge, attitudes and behaviors. There are some data to suggest that public awareness programs can impact knowledge and attitudes; there is scant evidence describing the best strategies for promoting the behavior changes needed to prevent, diagnose and treat urinary incontinence.

There has been very little work on how to monitor the success of continence promotion and public awareness, education of professionals, international organization initiatives and delivery of continence care and services. Education for the public and for professionals is simplistically assumed to be a good thing in its own right. However, there has been little debate on outcome criteria, and on what constitutes success or progress. It is vital that the ultimate goal of improving care and quality of life for incontinent people is kept to the forefront - none of these other activities makes sense except in that context.

This chapter attempts to summarize the current information available on promotion of continence awareness, professional education, and organization and delivery of services for urinary incontinence. Fecal incontinence has not been addressed in this chapter.

II. PROMOTION OF CONTINENCE AWARENESS

1. BACKGROUND

The 1992 clinical practice guideline on Urinary Incontinence in Adults of the USA Agency for Health Care Policy and Research (AHCPR) added a section on public and professional education [2] AHCPR is now known as the Agency for Healthcare Research and Quality (AHRQ). This panel of experts recommended:

- Increased efforts to inform and educate the public about incontinence
- The public should be aware that incontinence is not inevitable or shameful but is treatable or at least manageable.
- Patient education needs to be comprehensive and multidisciplinary so as to explain all management alternatives.
- Research to test the effectiveness of patient education is lacking and essential.

Taboos on mentioning disorders of the bladder generally and UI in particular are gradually lifting in some cultures. Two decades ago it was almost impossible to have incontinence discussed in the media. Now popular magazines, local and national papers, radio and television cover the subject in some countries regularly. Many countries have run national or local public awareness campaigns, usually spearheaded by a national continence organization. Many also have confidential help lines, which can be accessed anonymously. A list of international continence organizations is given in Appendix 1, and many are willing to share their experiences with others.

There is a need to evaluate the impact of public awareness campaigns. It cannot be assumed that everyone who has a continence problem would want or welcome information.

The World Wide Web provides a convenient source of health information for a minority of consumers. There are more than 10,000 health related sites, but all information may not be accurate and timely. Some believe that persons with incontinence might get valuable advice and comfort by using interactive services such as email [3].

2. QUALITY OF DATA (*Level of evidence-4)*

There is a great deal of published information on building public awareness of incontinence but very little to no information of the effectiveness in changing the public's attitudes and knowledge about the problem and health-seeking behavior.

3. CONCLUSIONS AND RECOMMENDATIONS - *(Grade of recommendation D)*

1. Continence organizations are often pivotal in stimulating and maintaining awareness. Many countries, including many developed nations, have a very low level of public awareness of incontinence and have not had any public awareness activities. There has been great progress in some countries with active continence awareness program. There is growing knowledge about what works and what does not.

2. The goal should be to promote health-seeking behaviour using simple language and terminology (e.g. bladder health, bladder control, overactive bladder). Public awareness should convey the messages that:

- Healthy bladder habits may help to prevent problems
- Bladder control problems are common and affect all ages and both sexes
- A problem with bladder control is a medical condition that can be investigated and frequently improved or cured.
- Bladder control problems are not inevitable.

3. There is a need for research on the best route for the delivery of the message and on the appropriate vocabulary, message and format in different cultures. For many it will be more appropriate to refer to "bladder control" than "incontinence." There is also a need to identify routes for obtaining health information in each culture.

4. There is a need for research on the long-term consequences of ignoring incontinence.

5. There is a lack of evidence on translating awareness into behavior change and triggers for health-seeking behavior. Success of campaigns should be measured by behavioral changes, and ultimately by improved patient outcomes.

6. There can be conflict of interest issues with public awareness, particularly where the motivation for funding a campaign is product or practice promotion.

7. Evaluation and outcome measures should be built into all projects and their funding.

8. There is a need for research to substantiate the benefits of preventive strategies.

9. The potential role of peer educators in developing countries should be explored.

a) Primary Prevention of Incontinence

There has been very little work on the prevention of incontinence. There is a lack of epidemiological studies focusing on the identification of risk factors for developing incontinence. Primary prevention strategies should be focused towards preventing UI from occurring [4]. Any activity taken for primary prevention of incontinence serves the target of promotion and awareness. Therefore, primary prevention can be viewed as another means for promotion of awareness of continence.

Identification of continent individuals who have the potential for becoming incontinent is one important primary prevention activity. Some risk factors have been clearly identified (e.g. more than two vaginal deliveries for stress incontinence). Interventions recommended to prevent incontinence through the use of pelvic muscle rehabilitation or caesarean deliveries may prevent future stress incontinence. Prevention should include education about behavioural changes that increase the probability of continence, the normal functioning of the urinary tract, expected age related and developmental changes, and how to find the appropriate treatment providers.

Primary prevention should be the target of all healthcare professionals as it means taking an active part in preventing its appearance. All preventive measures require a high level of community awareness, public education and health professional education [5] The process of storing and expelling urine is shaped by social rules for acceptable times and places for elimination. This may well be one of the main reasons why shame and denial of the problem are some of the main barriers for seeking medical attention.

From the literature and from previous survey results it is clear that there is a lack of public knowledge and awareness about the concept of incontinence as a medical problem that is common and has negative effects on quality of life, economics, social functions, etc [6] The public is not aware that incontinence can often be cured with conservative, non-invasive or minimally invasive techniques.

Studies looking into risk factors for incontinence are scarce and sometimes conflicting. One study in older men showed an increased risk for urinary incontinence in post-prostatectomy and hip fracture patients [7]. In elderly women, risk factors were hysterectomy after the age of 60 years, age (odds ratio 1.3 per 5 years); higher body mass index (odds ratio 1.6 per 5 units), history of stroke (OR 1.9), diabetes (OR 1.7), chronic obstructive pulmonary disease (OR 1.4), and poor overall health (OR 1.6). In frail older persons in nursing homes, other risk factors included incontinence and poor adjustment to the nursing home at two weeks post admission, and both mobility and cognitive impairment at two months post admission [8] In 100 hip fracture patients, men had a higher incidence of incontinence than women (48% versus 24%, p. <0.03). Individuals with cognitive impairment also had higher incidence of incontinence (56% versus 25%, p <0.03) [9]. It has been reported that UI in Caucasian, community dwelling older persons is associated with reports of poor self-rated health, after adjustments for age, comorbidity and frailty [10]. Another report lists antecedents of UI including impaired mobility, impaired cognition, poor pelvic muscle tone, lack of access to bathroom, decreased fluid intake, medications, lack of knowledge regarding normal functioning, abrupt changes in cognition, functional status and physical health, depression and social withdrawal [11]. Primary prevention strategies should be addressed for these high-risk populations.

An expert consensus meeting on prevention of incontinence made the following recommendations on promoting prevention education to the public, although it was recognized that these have yet to be substantiated by research [12].

1. The general public should be informed about healthy bladder habits and when/how to seek help.

2. Parents should know about the possible effects of toilet training practices and attitudes.

3. Teachers and schools should be informed about the importance of healthy bladder habits and appropriate toilet environments.

4. People with neurological disease (and their doctors) should know that management is possible.

5. Relatives of people with existing incontinence might prove the most receptive and relevant audience to target with a prevention message.

6. More research is needed to determine the most effective delivery of continence health education.

The group felt that it was important to target the prevention message to government bodies (especially health departments, but also education and employment), health insurance companies and other health funders, national organizations and societies whose members may have continence risks (e.g., organizations of people with neurological diseases), health professional organizations and commercial companies producing continence-related products. Persons at the administrative and clinical level need to be educated about the basics of urinary health and precipitating factors for incontinence before attempting to impart a prevention message.

b) Educating the public about continence

There is little research investigating public education to promote continence. Building awareness among the general public is usually attempted via the media. Using the media to disseminate information in the form of Public Service Announcements (PSAs) has been used extensively in the USA to promote AIDS awareness and as anti-smoking campaigns. In 2001, National Association for Continence (NAFC) produced and disseminated television PSAs to 380 media markets in the USA for the purpose of promoting continence awareness

In many cultures, one of the best vehicles to reaching the public is through an informed journalist. Journalists often use a "media hook," an interesting story that will take priority over other news on the television, radio or newspaper. Having a spokesperson with the problem or finding a celebrity who is willing to speak for the cause can help. These individuals can act as "influence leaders."

A promotion program for raising awareness must consider several aspects:

- **Target population –** Population studies reveal that older women followed by younger women are most affected by incontinence. The prevalence of UI and the lack of knowledge about incontinence are sufficient enough to justify a health-promotion program without segmentation by age or gender [13].
- **Target issues -** A promotion program should identify the issues that warrant promotion effort as well as barriers to promotion. Issues such as lack of willingness or readiness to seek treatment prevent women from seeking help [14].
- **Content of promotional material** -Any type of advertisement that deals with incontinence, even advertising campaigns for absorbent products can have a positive impact on lessening taboos against talking about incontinence. This increased willingness to discuss UI can be followed by advice on effective methods of coping with incontinence followed by directing patients to more effective methods of coping with incontinence.
- **Channels of communication.** Health care professionals may launch campaigns to increase practice revenues. Commercial companies often fund public campaigns in order to sell their products. Regardless of motivation, care should be taken to avoid raising public expectations beyond what the products or services can deliver.
- **Outcome assessment.** Prior to implementing an UI awareness campaign it is important to identify outcome variables that will evaluate its effectiveness.

c) Funding public awareness

Raising money for public awareness is often difficult. In some countries there are numerous granting charities. However, like the general public, these foundations are seldom aware of the impact of incontinence. Therefore, before starting public awareness campaigns, groundwork is needed to educate potential grant-givers. One way to do this is to publish a newsletter and to personalize letters to all of the staff at these organizations. Another is to offer to be a grant reviewer in order to promote better understanding in funding priorities and to stimulate proposals for incontinence that meet those priorities.

In countries where provision of continence products is only by a government funded health service (e.g. UK), there tend to be poorly developed retail markets with little commercial advertising directly to the public. This may limit public awareness about incontinence. Many countries also prohibit public advertising of prescription medication, so companies are forced to create awareness of their product and demand for treatment through indirect public awareness campaigns.

There are many opportunities for collaboration between commercial companies and not-for profit organizations. Companies wish to expand their market and have more incontinent people or caregivers come forward for help. Organizations aim to build public awareness.

d) Examples of public education campaigns in the USA

In order to get correct information to the public, and to allow persons to get their questions answered by a professional, the "I Will Manage" program was developed by the Simon Foundation for Continence. This program was modeled after the American Cancer Society's program "I Can Cope" and was marketed to professionals as a tool to promote continence at the community level. The program was designed to be multidisciplinary and included lectures and a small group format [15]. However, this program was not widely used by professionals in the USA.

The Oklahoma State Health Department developed “Dry Anticipations,” which was a community demonstration project that included a curriculum on UI for small groups of elderly women. [16] This project had three components: an educational intervention with physicians, an educational campaign for the general public and a test of behavioral treatments for older women. It was implemented by contracting with six sites in Oklahoma using a train-the-trainer model. A train-the-trainer approach, in which a project prepares a group of instructors to deliver an educational intervention to members of a target population, is a useful method when one wishes to introduce an intervention into existing agencies or ongoing social settings [17], [18].

In the last 5 years, promoting continence to the American public has exploded, primarily because of direct to consumer advertising that uses print, TV and radio marketing. This advertising is primarily developed and funded by pharmaceutical companies. Of course, in other countries such as the Netherlands, law bars the advertising and promotion of prescription drugs. In the USA each fall, a particular bladder condition is highlighted during “Bladder Health Week”. Twice in the last ten years, UI has been the featured topic.

e) Other national campaigns

An interesting campaign has been New Zealand’s “Dry Pants Day”. In Auckland a continence product fashion show began with fully dressed models who then stripped down to their incontinence products to demonstrate how well the products fit and how easy to disguise they are. The narrator told the audience about price and absorbency. Throughout New Zealand, stickers were placed on the inside of public toilet doors encouraging people, in honor of Dry Pants Day, to do their pelvic muscle exercises. No outcomes were measured.

In 1998 the Commonwealth of Australia granted AU$15 million (Australian dollars) for improved continence management in elderly care, targeting those persons living at home. The Advisory Board to this grant included professionals, consumers, caregivers, and organization representatives. Projects are funded under four phases: public awareness, education and information, prevention and health promotion, quality of service, and research. National Continence Awareness Weeks will be held in both 2001 and 2002 but similar activity in each of the last 10 years has not has significant impact. Among the various consumer projects is the Public Toilet Map – a national mapping of toilets to assist travel for persons with incontinence that will show information about opening hours and disability access. Each funded project is independently evaluated or has inbuilt outcome measures.

In Belgium, patients, caregivers, and industry founded an interest group to coordinate activities. It was named “Ucontrol” indicating “you can be in control.” The purpose of Ucontrol is to improve incontinence by giving information to patients and caregivers and by supporting and combining coordinated actions involving various government authorities. Ucontrol includes a permanent telephone line, information leaflets which can be obtained free of charge and posters for waiting rooms and hospitals. The organization has prepared a workbook for family doctors, which offers practical information on diagnosis and treatment of incontinence and when to refer for specialist investigation. Ucontrol has published articles in all major Belgian newspapers and magazines and has organized public talks for organizations of women and caregivers, schools and the general public. A scientific organization was formed to provide communication, quality control and continuous post- academic education for the different professionals who provide incontinence services.

f) Public awareness materials

The interventions that best reach the public and trigger the desired behavior seem to vary between countries and cultures. The Japan Continence Action Society held a “Toll Free Telephone Clinic” and callers were asked how they heard about the line. Sixty five percent replied from a newspaper; 26% from television and 8% from a poster. In a United Kingdom (UK) campaign it was found that newspapers were by far the most common source of information, followed by radio [19]. Television and newspapers work best in Singapore, with a cured patient bearing testimony to former suffering and its alleviation having the most impact. In the USA, television advertising targeting overactive bladder and funded primarily by pharmaceutical companies, has yielded a significant response. Nationwide TV reaches more people than the circulation of any single newspaper or the distribution of a booklet even through physician offices.

Experience from a toll-free help line in Australia suggests that television exposure produces a better response than radio, Sunday newspapers are better than dailies, tear-off reply slips are well-used and engaging a celebrity as a spokesperson is more effective than a doctor or nurse. The Australian toll-free help line started with a $A5,000 donation and ran for 18 months before attracting a major ($Australian 900,000) government grant. The Australian Continence Strategy grants have covered multiple projects including epidemiology of incontinence, outcome measure, toilet surveys and service delivery. The words “continence” or “incontinence" are poorly understood and simpler terms achieve greater public recognition in many languages and cultures. The use of overactive bladder in advertising has increased reporting of the condition to primary care professionals in the USA.

Little evaluation of the importance of leaflets or brochures has been undertaken. An information booklet has been found to improve patients' knowledge, acceptance and management of an indwelling catheter at home [20]. More evaluation of the impact of educational materials is needed.

g) Evaluating the effectiveness of public awareness campaigns

It is important to assess that all the efforts to educate the public have the desired effect, and to define the criteria by which to judge "success." Measures of success could include the number of media "impressions" through newspaper, television or radio, the number of people who sought help or the numbers who were actually helped. The message should be crafted to encourage and motivate the desired action. A questionnaire survey of callers three months after phoning the Continence Foundation UK help line during National Continence Week 1994 found that callers appreciated the information, but did not necessarily act on it [19].

A media campaign should use multiple channels to insure the broadest coverage [16]. An initial channel should include press and radio. A second channel would be specialized age and health publications. A third channel is the use of posters and brochures placed in physician's offices, hospitals, senior center, pharmacies and churches. A final channel is direct presentations to the public, such as at senior centers.

In France, the effect of health education was evaluated in a randomized study in sheltered accommodations for the elderly [21]. Twenty centers were randomized to a single one-hour health information meeting or control group. During a 30-minute talk a nurse encouraged people to visit a doctor if they had urinary problems. A questionnaire three months later found that the experimental group were much more likely to have had treatment if they were incontinent (41% vs. 13% controls) and 82% said that they had received some information about incontinence in the previous 3 months (compared to 22% controls).

A health promotion project called Dry Expectations was developed and implemented in six ethnically diverse, predominantly minority, and inner city senior centers in the USA. The program was designed to address an older population. The project consisted of three phases: orientation and training of key staff members/peer educators at the centers (train-the-trainer model); educating seniors through four one-hour weekly sessions involving visual aids and completion of bladder records and quizzes; and follow up sessions with senior staff/peer educators to reinforce the previous training. The program was very well received by the participants and roughly 80% felt they had more control over their bladder by the end of the last session [22].

This project was recently expanded to determine the health promotion needs of senior citizens concerning bladder control issues. Focus groups of older adults attending health seminars in an urban, community setting were conducted. The primary objective of the project was to determine the understanding of older adults in the areas of general health and their beliefs surrounding the problem of UI. The 81 participants were predominantly African-American women representing all socio-economic levels. Seniors expressed confusion when asked if "overactive bladder, bladder control issues and urinary incontinence" were the same condition. Most seniors said they felt comfortable about discussing bladder control issues but most admitted that their doctor had never asked them, nor had they raised the issue. However, they did discuss UI with family members and friends and they were aware that many persons with whom they socialize might have a problem with UI. The majority of seniors answered "no cure" when asked if treatments were successful [23].

A 1996 survey of community-based incontinent people by the National Association for Continence (NAFC) showed that on average women wait 3 years before seeking treatment while men wait only 6 months [24]. This survey also indicated that when women did tell their doctor or nurse about their problem many were told to "live with it". The most common reasons cited for failure to seek treatment are either that incontinence is not seen as abnormal or that there is a low expectation of benefit from treatment. A 1999 NAFC membership survey (mailed to 98,000 consumers with 2,000 surveys returned) indicated that 62.1% registered dissatisfaction with treatment outcome [25]. Only 3.3% of all respondents considered themselves "cured" following their most helpful treatment and only 6.8% overall explicitly expressed that they were "very pleased" with their outcomes. It appears that a gap continues to exist between outcome objectives of consumers and what is available among preferable treatment options.

h) Taboos and health-seeking behavior

Triggers for health-seeking behavior are complex and multifactorial. It is beyond the scope of this chapter to review these here. With a chronic problem like UI, it is important to understand what triggers the patient to consult. Many people also do not consider themselves "incontinent," as this has a negative connotation, or is not well understood. For this reason it may be better to use non-technical terms in most languages and cultures.

Incontinence and bodily functions remain taboo in many cultures. In a series of in-depth interviews with 28 young and middle aged women with urinary incontinence, it was found that incontinence was considered a taboo, making it difficult to seek professional help or even to focus on and think clearly about [26]. Some reacted with apathy; others were always on the brink of taking action. Some feel guilty or associated with despised groups. Many worked hard to maintain "normalcy," and hide the problem. For some there was defensive denial, or they subordinated the problem to other priorities.

One of the aims of a UK study was to explore why people with urinary symptoms (incontinence, urgency, frequency and nocturia) sought help, particularly to identify the triggers that caused them to seek help [27]. The most frequently cited reason for seeking help was raised awareness. The authors postulated that this suggests that health promotion campaigns could be effective and raise not only awareness but also demand on services.

i) Non-compliance: Guilt and Apathy

Pelvic muscle exercises are often recommended post partum. The evidence that these exercises can prevent incontinence is not conclusive but is promising [28]. Patients often do not comply with the advice. A study of in-depth interviews found some recurrent themes [29]. Women often felt guilty that they had not done the exercises, and were subsequently apathetic about the possibility of help for incontinence. Non-compliance with exercises was seen as a reason to expect no further help from doctors, made patients feel embarrassed and was a reason for inaction. Women have found these exercises difficult to remember and to do. If exercises had not been done this was seen as an irretrievable past error that must now be lived with. Consequently many women find themselves in a situation that they feel is their own fault - because exercises were not done, were not done correctly. This led to apathy and reluctance to seek help. Women have a perception that health professionals will blame them for their incontinence.

Self-interest may be a motivator for public education. Direct advertising raises public awareness to advance sales and to serve a commercial advantage. In Australia, medical entrepreneurs advertised widely in the press to promote urodynamic centers and in doing so stimulated the inception of the Australian Urodynamic Society. Such profit-motivated initiatives may also have the effect of raising the profile of incontinence as a health issue, to the benefit of all. It is unrealistic to expect industry to be totally altruistic. Continence organizations may consider partnering with industry to reach a wider, general public audience.

III. PROFESSIONAL EDUCATION

1. BACKGROUND

A comprehensive service will only work well if those responsible for primary health care are educated about incontinence and know how to refer appropriately. However, professional education with reference to urinary and fecal incontinence remains only a small part (if any) of the basic training of medical practitioners, nurses or allied health professionals. An early survey in the UK found minimal attention given to incontinence in both medical and nurse training, and a key recommendation for improving continence care was an increase in quality and quantity of professional education [30].

There is a dilemma in most countries as to whether to educate the public or the health professional first. In some places it is felt unfair to raise false expectations among incontinent people by creating awareness without having knowledgeable professionals or services already in place. But it may be argued that it is necessary to stimulate professional interest by creation of public demand for help. Ideally, the two would develop together, but this is not always realistic in practice.

Survey results indicated that in most countries incontinence is covered little or not at all in undergraduate medical education and only selectively in postgraduate training [6].

2. QUALITY OF DATA- *(Level of evidence - 4)*

There is a paucity of published work on professional education in the realm of urinary or fecal incontinence. Similarly there are few studies addressing the effectiveness of education either in improving the knowledge base of the learners, or in whether there are changes in the standard of care for patients, or the outcomes of their interventions.

3. CONCLUSIONS AND RECOMMENDATIONS - *(Grade of Recommendation - D)*

1. There is a dilemma as to whether public or professional education should come first. In countries where continence has not been developed as a medical service, professional education will usually need to precede public awareness.

2. There should be compulsory inclusion of incontinence in undergraduate curriculum (doctors, nurses, physiotherapists, pharmacists, and others). Incontinence must be identified and planned and preferably delivered as a separate topic, not fragmented between different modules of the educational curriculum.

3. There must be specialist education programs, with relevant accreditation mechanisms (and planned periodic re-credentialing) to safeguard patient interests, for urologists, gynecologists, specialist nurses, physical therapists and others.

4. Funding of education needs to be addressed.

5. There is a need for research on translation of education and research into improved clinical practice and how to ensure that this happens.

6. There needs to be research into mechanisms for increasing professional motivation to acquire education and improve performance.

a) Medical professionals

Most physicians have received little education about incontinence, fail to screen for it and view the likelihood of successful treatment as low [31]. When most of today's professional leaders were undergraduates, UI had almost no part in the medical curriculum. Gynecologists in the course of taking a history occasionally mentioned the term incontinence, but there were no lectures on the subject. Many urologists had no interest or practice in the continence sphere and those that did regarded urinary incontinence as being a post-graduate rather than an undergraduate subject. Bladder and pelvic floor anatomy is poorly covered in preclinical schools and relevant physiology is not mentioned.

- **Medical Undergraduates**

Many undergraduate curricula include information about incontinence. Incontinence may appear in the geriatric medicine, gynecology or urological sections of the curriculum. While co-ordination between the disciplines is rare, some give joint seminars on urinary and fecal incontinence (University of New South Wales) and physiotherapists may have an input to the curriculum (University of Newcastle). Most students today learn about pad and bell alarms for enuresis training, but that is often the extent of their pediatric continence knowledge. In few medical schools are undergraduates exposed to more than five hours of lectures or tutorials on incontinence in the 5-year medical course. In a 1995 survey in UK, undergraduate medical students received an average of 3.3-hours on incontinence causes and treatment, compared with 4.2 hours for physiotherapists and 9.4 hours for pre-registration nurses [32].

It may not be realistic to expect more input than this, given the overburdened medical curriculum. In-depth education may be best given at the postgraduate level for those who will manage incontinence in clinical practice.

- **Family doctors**

The training of family doctors is extremely heterogeneous, varying between different regions and nations. In the UK, two-thirds of newly qualified family doctors received between 1 and 4 hours of training on incontinence; one third had no training at all [33]. Ninety-two percent of doctors in practice for over 5 years had received no training on incontinence and 80% of all doctors felt that their training on the subject was inadequate. Ninety-two percent expressed a desire for specific postgraduate education on incontinence. Knowledge about incontinence was found to be limited, with 76% having "no idea of its prevalence." Only 30% of family doctors felt confident diagnosing and managing incontinence.

There have been few concerted efforts to educate family doctors. However, in Australia in 1989 the New South Wales state government gave $A25, 000 (approx. US$ 18,000) for the development of an educational kit on incontinence [34]. The Australian Federal Government ultimately funded 15000 copies to be distributed to all family doctors in the country. The evaluation of that educational program showed a significant retention rate among 124 volunteers, 80 of who got the pack and were compared with 44 controls [35]. There was no difference in initial knowledge between the groups, but there was a significant difference in post-pack scores between the groups with no difference in scores on questions not in the pack. Sixty-three percent continued to use components of the kit later in clinical practice. However, the study also found a great lack of interest, in that only 16% of those initially selected randomly agreed to participate.

A similar study conducted in 2001, showed a similar initial lack of interest among family doctors. However, after using an educational flip chart and lectures over one evening, family doctors and their practice nurses, showed significant changes in their attitude, with 64% indicating that they would adopt a more pro-active role in the future. Only 10% remained disinterested after the educational intervention [36].

Family doctors can be effective in treating incontinence by conservative measures when educated and motivated [37], [38]. Typical cure or improvement rates range around 60 - 70%. Education can also increase referral rates to specialist practitioners [39]. However, the best format for education needs further delineation. It gas been found that videos are not necessarily the best format for use in primary care practices. It is not known whether commercially produced videos are more successful in reaching their target; some may be, especially when the company has a sales force actively promoting the videos. As the price of video reproduction has come down, many companies are now prepared to give them away free, even for individual patients.

The 1992 and 1996 USA AHCPR clinical practice guidelines were produced to help to standardize the assessment and management of urinary incontinence in adults [2,40]. Aimed at health professionals the guidelines are widely quoted, but they failed to inform the practice of medical practitioners or their trainees [41]. The concept of using bladder diaries or checking post-void residual urine as part of basic assessment is still foreign to most urologists, gynecologists and family doctors not specializing in continence. Nurses seem to have taken up the AHCPR recommendations, incorporating them in curricula, evidence-based clinical practice and care pathways, whereas doctors have not [42], [43]. In a USA survey, 50% of physicians in the USA who treat bladder disorders (25% of which were family practice physicians) were not familiar with the AHCPR guidelines [44]. Although UI is prevalent it mainly goes underdectected and is inadequately managed. Physicians are inquiring about incontinence in only a minority of their at-risk patients.

Changing the current patterns of medical care with respect to detection and management of incontinence will not be easy [45]. Guidelines for medical practice can contribute to improved care only if they succeed in moving actual practice closer to the behaviors the guidelines recommend [46]. Unless there are other incentives or the removal of disincentives, guidelines are unlikely to effect rapid changes in actual practice. It is recognized that other tools or strategies are needed to augment and build on educational endeavours [47]. Strategies that aid in implementation of a guideline include reminder systems to remember when to implement guidelines, tracking systems to identify patients who need follow-up and continuous quality improvement monitoring and regulations. Educational programs alone may change knowledge and attitude but rarely change behaviors. Guidelines combined with continuing medical education programs may be more successful [48].

Even evidence-derived guidelines may not always result in better practice or outcomes. The implementation and evaluation of such a guideline in one family practice from which 1503 patients were selected randomly has been reported [42]. Thirty-five percent of women and 9.9% of men suffered from incontinence in the previous 2 months, but 61% had never sought help. Of those who did, 63% were referred on mostly to specialists. Only 53% had a urine test, only 1 in 4 women had a vaginal examination and only 4 of 206 persons with UI had done a frequency/volume chart. After implementing the guideline, two abdominal examinations and one new rectal examination were performed, but no new vaginal examinations were performed. Frequency/volume charts were given to three people. Two people used less drugs. The severity of incontinence was not changed following the intervention. Family doctors did not effectively implement the guideline. It remains to be tested whether, properly used, guidelines can improve incontinence in practice.

In a 1999 repeat of a 1996 survey, among 6481 patients (>50 yo), it was found that after numerous UI awareness and education campaigns, German physicians were even less likely to address incontinence [49]. The “don’t ask, don’t tell” attitude between physicians and patients, has fiscal implications for managed care. The consequence of not treating the condition may increase the annual cost of care by an estimated $3941 per individual [50]. Funding for conservative management of UI, or better-informed public demand, may stimulate more interest and improved performance among this pivotal group.

If family doctors are to be engaged in continence care, they need to be involved in the process and it’s planning. As clinical encounter time is limited, there is a need for a validated assessment tool to aid in the assessment of a patient. The family doctors need effective, practical treatments relevant to their care setting.

- **Medical Specialist Training**

Specialist training in incontinence is not always adequate to their needs in subsequent clinical practice. A survey of urological trainees between 1988 and 1994 in Australia showed many felt their training in the management of incontinence (and infertility) had not been adequate [51].

Much the same can be said of continuing medical education for already-credentialed specialists who are erroneously assumed to know something about the subject from their training. The Colleges of Obstetrics and Gynecology in the United Kingdom and Australia and the American Board of Obstetrics and Gynecology have developed courses and credentialing of specially trained urogynaecologists with separate examinations. However, incontinence may be in danger of being seen as the province of an elite group of super-specialists who get further and further away from their colleagues.

A recent survey of 163 urodynamic services in the UK found that only 43% of doctors, nurses and others performing urodynamic investigations felt that training to do these studies had been adequate [52].

The plethora of meetings put on by medical specialist groups (International Continence Society, Pelvic Floor Society, Asian Society for Female Urology, International Urogynecology Association) and meetings of recently-formed national Continence Foundations in Thailand, the Philippines, Taiwan serve both as stimulants to trainees, and as continuing education for practicing clinicians.

b) Other medical professionals

Nurses have often been more closely involved in continence care and management than physicians or allied health professionals. Those dealing with the elderly at home (through domiciliary nursing services), in hostels, nursing homes or geriatric institutions are especially familiar with the problem. Only in the last 15 years has education really empowered nurses to intervene to change the continence status, rather than coping with its consequences.

Nurses called "Continence nurse advisers" were appointed in the UK throughout the 1980s with no central planning or direction. In 1983, there were only 17 continence advisers, [30] by 1998 there were over 420 [53] with nearly every purchasing authority having at least one in their area. Some cynics claim that the program was created to reduce spending on incontinence absorbent products, which have traditionally been provided, free of charge in the UK. Most continence nurses have developed a service in which individual patients are seen and assessed in hospital, at home or in community clinics, as well as offering professional advice and support to colleagues.

The Royal College of Nursing Continence Care Forum conducted a consensus exercise amongst continence advisers [54]. Recommendations were that the principal functions of the continence adviser should be education, management, clinical practice and research, and that each of these elements should be recognized as equally important. At present there is no research on the most appropriate mix of these functions, nor on the optimum caseload or number of continence advisers per population. Most areas seem to be moving towards a small team to cover a geographical area rather than a lone individual.

The UK Department of Health has commissioned a survey of continence nurses which found that most had both hospital and community responsibilities. Ninety percent were involved in clinical practice, advice and training, but fewer in management and research. Only 20% were involved in all 5 of these. There was a wide variation in the amount of time and the importance ascribed to different activities. Seventy-three percent carried a personal caseload. Eighty-five percent did home visits and 65% ran a clinic. Thirty-eight percent ran a telephone advisory service. Many had developed a link nurse network in each clinical unit to encourage liaison. Most worked as part of several different multidisciplinary teams. Gaps in the service were identified as children, people with disabilities and those with mental health problems. Few referrals were from ethnic minority groups. With time many had moved away from clinical work towards education and training, and towards developing a team of advisers [55].

Other countries, such as Australia, have adopted this model of a continence nurse specialist. Australia provides domiciliary continence services via the District nursing service or geriatric assessment teams. The Continence Foundation also runs centers in several state capitals. The Netherlands has a well-developed system of continence nurses, and Scandinavia has a university course requirement to practice as an "Urotherapist."

The specialist nurse role varies from independent nurse practitioner, continence consultant on call to other generalist domiciliary nurses, appliance specialist, assessor, trainer or therapist. Funding arrangements may determine whether and how a specialist nurse post can be developed. For example, in Singapore, most posts have started in large hospitals because that is the source of funding.

There are health care systems that make it very difficult to fund nurses working as independent practitioners across hospital and community boundaries. Elsewhere, the prevailing culture and philosophy within nursing does not favor the development of specialist roles. For example, historically in Denmark the system prepared highly trained generalist nurses and did not encourage clinical nurse specialists [56].

In Canada, a Nurse Continence Adviser collaborative database has been set up. Information gathered during patient assessments is recorded on a standard assessment data entry form. The system generates reports and consultation letters and can be updated at each visit. There is a care-mapping feature, which allows evaluation of each patient's progress against expected outcomes, facilitating audit and comparison between advisers. The system is reported to have reduced paperwork by 75% [57].

- **Specialist Nurses**

As has been previously noted, much of the change in the role of nurses has come about through the emergence of nurse continence advisers and to a lesser extent, special interest groups within stoma (enterostomy) therapy. Educational courses on incontinence are available for nurses are in the UK, USA, Europe and Australia and are beginning to appear in Asia, notably Hong Kong and Singapore. These courses vary from 2 to 4 weeks face to face didactic courses to distance learning courses lasting 4 - 6 months and leading to a post-basic nursing certificate. Australia has a graduate certificate course for continence nurses, as well as a variety of distance learning and certificated courses. A 1-year graduate certificate course is available at several university Schools of Nursing within Australia - in particular, Flinders University of South Australia, Univ. of Western Australia, University of Technology Sydney and Deakin University. At Flinders, the Certificate in Continence Management can be upgraded to a Master degree after 2 years of further study and research. Integral to some of these courses has been instruction in educational skills that enable the graduates to teach not only other nurses, but also patient and caregiver groups.

This accords with the needs in the community and the emerging role of the continence nurse practitioner (CNP). The English National Board has defined a role and an appropriate curriculum involving introduction, clinical practice, and health promotion and bowel dysfunction. The course evaluation was by controlled trial in which graduates were shown to improve knowledge scores from 18(38%) to 25 (53%) [58].

There is a need for properly validated courses as a prerequisite to practice as a nurse specialist. The University of Gothenburg has a well-established multidisciplinary course for the recognized qualification of "Urotherapist," of whom there are several hundred throughout Scandinavia. Most participants are nurses or physiotherapists, but there have also been some doctors who completed the training. In the USA, nurse practitioners are prepared at the graduate nursing level, but there are few nurse practitioners specializing in incontinence care [59]. In many other countries, recognized preparation is not in place, and any one can potentially claim to be a continence specialist.

The Japan Nurses Association has an accredited 6-month specialist course on wound care, ostomy and continence nursing, but the emphasis is on stoma nursing. The course costs $Y750, 000 (approximately American$ 5,500) and 90% of attendees pay their own tuition fees. The Japan Continence Action Society also provides 4-day primary and secondary courses. The Danish Nurses Organisation has a 220-hour course, divided into 5 modules [60].

In Canada, 38 nurses were trained in a 3-month program funded by the Ontario Ministry of Health in 1995. This was found to be expensive, so McMaster University, with local preceptors and a tutor available developed distance learning Nurse Continence Advisor education program by phone. Assignments are posted on-line. The students have 6-9 months to complete the course, which has so far enrolled 34 students, for the same cost, as training four students under the previous program. It is planned to offer this distance learning on a national basis in 1998 [61] The same group has developed standards for management, clinical practice, education and research [62].

The funding of educational continence programs in incontinence by governments will inform both the need for CNPs and the types of service they provide. Non-surgical treatment remains under-recognized and poorly reimbursed in the USA, where the demands for CNPs is low, whereas in many other countries (e.g. UK, Europe, Australia) CNPs are not only funded, but also are highly regarded. The potential roles of CNP's as clinical providers, advisors, educators, researchers and managers, [55] and the relative need for each skill, will inform curricula of certificate courses in the future [63].

- **General Nurses**

Setting nursing standards of practice can help by requiring clinicians to acquire the skills to meet the standards. In Australia, for example, government funding to nursing homes is dependent upon their reaching certain standards in continence assessment and management. The standards set were those based on advice from the Continence Foundation, which was commissioned in 1991 to produce an educational resource for nurses working in elder care [64] which was distributed to 1400 nursing homes. Changing negative attitudes among health workers and low expectations amongst elderly people themselves are among the obstacles to such educational endeavours [65]. Nursing records, which are designed to extract and document continence status, may assist the nursing process [66].

The development of Continence Care Pathways has been tested and found that the use of care pathways ensured that generalist nurses identified reversible causes (e.g. UTI, drugs, fluid intake, constipation, dexterity and mobility issues), and addressed quality of life, bothersomeness and specific symptoms [67]. Patients could then be referred to CNPs for specific treatment beyond the scope of the generalist nurse, or when they failed to respond to first line therapy. The care pathway identified the needs of the patient, directed simple investigation and primary therapy, but also identified the resources needed by the nurses (e.g., urine testing dipsticks, lists of drugs, frequency/volume charts). The pathway could be modified according to the equipment and expertise locally available. Educating large numbers of general nurses to follow a simple pathway with basic continence-care competencies [68] may make better use of a CNPs time and specialized skills [69].

The level of knowledge within the general nursing community appears to be less than ideal in both the USA [68], [70] and Sweden [71]. Many non-specialist nurses desire, and have a need for, more education about what they can do to better manage incontinent individuals. Moreover, the quality of life of the incontinent nursing home resident is often more dependent upon the skill, education and attitude of the nursing aide than of the nursing unit manager.

In a detailed UK study of learner and qualified nurses' knowledge and the content of nurse education, only 12% of qualified nurses had received any education on incontinence in the previous 12 months, and for those who had, most was on products. Forty-four percent of charge nurses and 81% of staff nurses had received no additional training on incontinence since qualifying [72]. Further work on attitudes via a questionnaire to qualified student nurses on hospital wards found predominantly therapeutic, rehabilitative attitudes, but also a number of misconceptions. Twenty one percent thought their primary role with incontinent patients should be supplying products and 11% saw incontinence as an inevitable part of aging. Sixteen percent agreed that incontinence was often due to laziness and 28% thought that incontinence was more distressing for a younger than for an older adult [73]. In a further survey of trained student nurses, the author found that nurses still focus primarily on palliative rather than therapeutic care and lacked knowledge on which to base care [74]. However, nurses with a post-basic qualification or in-service education were more likely to have positive attitudes, although it was not clear whether this was as a result of the education, or whether these nurses already had a positive attitude and had therefore self-selected themselves to receive further education.

In the USA, although there are a growing number of nurses who are developing expertise caring for incontinent patients, there are no academic or clinical proficiency requirements to be considered a “continence nurse practitioner or specialist.” In 1993, the Wound, Ostomy, and Continence Nurses Society (WOCN) developed the first certification program for continence care nurses in the USA. To date, the number of nurses certified through this process has not been significant probably because of views of specific requirements. The norm is that most nurses in the USA obtain their knowledge and skill through self-motivated activities. A survey of nurses attending a national nursing conference on UI asked about educational preparation related to this condition. Respondents reported that less than half (40%) received academic education including course work in accredited post-baccalaureate or graduate programs related to UI. However, most nurses (76%) obtained instruction at professional conferences, continence clinics supervised by nurse practitioners or physicians, “on-the-job” training, self-study, or in-service programs [63].

These findings were supported by a national survey of USA nursing school curriculum [75]. Schools of nursing agreed that incontinence is important and 90% of curricula included it specifically, but with an average of only 2.1 hours of lecture time in undergraduate nurse preparation. There was no commitment to requiring clinical experience in this area, there was a lack of awareness of available educational resources and there were few experts available to teach. The authors offer evidence that incontinence is not well managed in clinical practice, suggest that 2 hours is insufficient and make recommendations for improvements and research on which instructional methods are most effective. Because incontinence crosses so many boundaries, it is difficult to know where to fit it into a curriculum as a coherent whole rather than fragmented between different modules.

Nurses are not always positive towards continence education, with 20% in one study feeling that nurses in USA nursing homes would be apathetic or resistant to a program on incontinence [75].

It is not clear how the need can be met in a timely fashion, or who will pay for the time and expertise it will require. Governments, as chief funders of nursing home care have a vested interest in promoting continence where it is possible. It is believed that the continent nursing home resident requires less nursing time than an incontinent resident. Expert intervention also has the possibility to reduce the need for, and cost of incontinence devices and products [77]. It therefore falls to the funders to underwrite the education that is needed to promote continence. More emphasis on incontinence care and the nurses’ role in continence promotion should be encompassed in basic nurse training courses. CNP’s and nurse continence advisors are the best instructors to provide this education. Fundamental texts on incontinence should get onto the reading lists of basic training schools and colleges [78], [79] [80], [81], [82], [83].

A clinical handbook has been found to be a good method of disseminating research findings to nurses [84]. A significant improvement in reported clinical practice was found for 86% of variables in the experimental group compared to a 59% improvement in controls. However, only 54% of those approached agreed to enter the study, and only 29% of them attended the second session, suggesting a lack of interest and motivation generally. As with physicians, it is felt that improving nursing knowledge will not actually translate into improved clinical practice, or into the ultimate goal of improved patient outcomes. A review of ward policies and community nursing practice in an area with a well-established continence service and education program demonstrated very little evidence that education had tangible effect on practice. The authors conclude that nurse specialists are most usefully employed providing a clinical service to individual patients rather than spending their time educating other nurses. [85]

There is a lack of consensus or guidelines on what it is reasonable to expect different nursing groups to be taught at each educational level.

c) *Allied Health Professionals*

Physiotherapists or physical therapists (PT) have long played a part in continence care and the management of incontinence. In some countries, patient self-referral to specializing physiotherapists has become commonplace. Physiotherapists' involvement in incontinence appears to be either on the basis of individual interest or through association with women's hospitals or obstetric departments, rather than as part of a general physiotherapy practice. As such they tend to be highly motivated and enthusiastic.

Post-basic PT education has largely been post-graduate through specialist courses run by specialists. In the UK, the University of East London has a degree level module run part-time over 15 months. Over 100 physiotherapists have completed this to date [86].

Pharmacists have a variety of roles to play in continence care. In Australia, they have been avid consumers of recent continence education programs. The public sees them as important and approachable sources of health information. Many retail pharmacies display health promotion literature on a range of subjects including incontinence. From such displays people can pick up the information they need without drawing attention to themselves. The pharmacist may also become the continence adviser on appropriate continence products. Liaison between continence organizations, continence advisers and medical practitioners may be an important avenue for promoting continence information into the community, often at no charge, or with the cost born either by the pharmacy chain or by sponsoring pharmaceutical houses. Educational seminars for pharmacists are generally well received.

There is also a need to address the training needs of unqualified nursing assistants and aides, particularly in the nursing home setting. In the USA of concern is the high turnover rate among first-line caregivers in institutionalized and in home care settings, making it economically difficult to maintain desired training levels. These individuals are nursing assistants who are the people providing incontinence care and who are the least trained.

Reimbursement schemes strongly affect who is the provider of intervention measures. In the Netherlands, for example, up to 14 visits to a physiotherapist are paid for by the government for incontinence (e.g., biofeedback therapy). Before 2001, there was little chance of getting coverage of biofeedback assisted pelvic muscle exercises in the USA.

d) Educational materials and funding

There is a range of teaching packs, videos, and books on the topic of UI available. The Continence Promotion Committee of the International Continence Society (ICS) publishes a directory of material available from national continence organizations. There have been many advances in the field of information technology and interactive and distance learning methods which are starting to be applied to continence.

One interesting innovation in delivering continence education was reported by Teleac, a Dutch broadcasting company, who offered sufferers training therapy consisting of pelvic floor muscle exercises, bladder training and advice on relaxation and posture. They reached an average of 140,000 viewers per broadcast; 51% of participants reported an improvement in their incontinence, and 83% were satisfied with the results of the course [87].

Education can be expensive, for courses or production of materials, and to replace personnel who are away from work. The first two specialist nurse courses in Australia cost AU$110,000 to train 20 nurses.

In practice much education and many materials are produced or sponsored by commercial companies marketing incontinence-related products. While some are highly ethical, and fund broadly based materials without product mention, others attempt to influence the content to market their product. A partnership between ethical companies and professionals can be mutually beneficial, but the boundary between education and marketing is not always clear.

e) Internet education resources

Many Internet sites now exist for the education of professionals and public. Providers have developed web sites and educational materials which are available in CDROM format (Japan) and as computerized decision pathways. In future, online real time video will be accessed through the Internet. The CONTInet, a site sponsored by the ICS, provides interchange between national continence organizations and the public. A number of sites now exist from trade and professional bodies providing up to date information about new products and operative interventions. Interactive educational sites have yet to appear. One study reported on the accuracy of web sites developed by organizations based in the USA that included information on UI [88]. A total of 265 web sites were located but only 15 sites met the inclusion criteria. The authors felt there is a rapid proliferation of information on the WWW and there is a need to critically evaluate new sites or updated information as it becomes available. A physician evaluated the Internet as a source of interactive information about UI by posing as a fictitious woman with symptoms of stress UI. He found that few sites provided comprehensive information, but most information was correct [3].

IV. ORGANIZATIONS

A. DELIVERY OF CONTINENCE CARE AND SERVICES

1. BACKGROUND

The organization of incontinence services in each country will depend on the organization and structure of health services generally. It is difficult to make recommendations that will apply in such a variety of contexts. In addition, incontinence is so widespread and affects so many different types of people that they can present for help to literally any health care professional. This means that there will seldom be one portal of entry to a continence service. The challenge is to plan a service that ensures a systematic care pathway (i.e., that patients follow a step-wise progression of investigation and treatment, without overlaps or omissions) and the best use of scarce resources [89].

When new services are created there is a temptation to focus on the high technology investigation and medical treatment elements without considering the infrastructure needed to support that service. However, there has never been a comprehensive examination of an optimal service. It is not known whether a hospital-based specialist-led clinic will achieve better and more cost-effective results than primary care clinics, domiciliary services or any other model.

In some health systems incontinence traditionally has been seen solely as a nursing problem, with little interest or input from other members of a multidisciplinary medical team. Except for a few isolated areas, the main intervention has been trying to help the individual and caregivers cope with symptoms rather than attempting to cure the incontinence. For example, in the UK it is common for an elderly person presenting with incontinence to be referred directly to the district nurse "for assessment for pads and pants," with no physical examination or further investigation considered.

In fact, incontinence is often a complex and multi-faceted problem, particularly in frail or dependent individuals and it may require input from a wide variety of disciplines to tackle it effectively. While it may not be practical for all specialities to work in close proximity, there needs to be careful consideration of who does what, with protocols to guide appropriate referral and ensure good liaison. It is important that there are neither gaps nor overlaps in the service. In countries such as Australia, New Zealand and the UK, where there is a national network of CNPs, part of their job is to organise this liaison, integrate services, and guide individuals through the referral route most appropriate to their individual needs.

Although some might see multidisciplinary working as the ideal, the reality is not always smooth. In some situations, rivalries and competition between disciplines and medical specialities is evident. This may be because of competition for patients and income, or because of disputes over the demarcation of the scope of different disciplines (such as the boundary between urology and gynecology, or between nursing and physical therapy). In Israel, physical therapists are not permitted to perform any invasive procedure (e.g. insertion of vaginal and rectal sensors and pelvic examination procedures are considered invasive and physical therapists are not reimbursed). Only nurses and doctors perform these procedures and examinations.

2. QUALITY OF THE DATA - *(Level of evidence - 4)*

There are no studies directly comparing the effectiveness of specific delivery systems for continence care. In certain cases, enthusiasts have conducted research. The results may not generalize to the wider setting. However, there are examples of models for service delivery in some countries. Others have combined the expertise of multidisciplinary to maximize service delivery.

3. CONCLUSIONS AND RECOMMENDATIONS - *(Grade of Recommendations - D)*

1. World Health Organization recognition of continence as an important health issue will encourage those countries with no current provisions to plan a strategy for meeting continence needs.
2. Government support and co-operation is needed to develop services, and responsibility for this should be identified at a high level in each Health Ministry. Incontinence should be identified as a separate issue on the health care agenda. There is a need for funding as an independent service, not to be linked to any one patient group (e.g. elderly or disabled), and not an optional service.
3. No one model for Continence services will apply. In all health care systems much will depend on the local health care structure. Given the high prevalence of incontinence, there is a need for a stratified service. There should be a community based primary health care continence service (family doctor or continence nurse led) to assess each presenting individual and to implement conservative treatment when appropriate. Specialist consultation and modern investigations should generally be reserved for those patients where appropriate conservative options have failed, or for specified indications.
4. Continence services should be planned according to the needs and wishes of incontinent people and their caregivers. Consumers should be actively consulted

and involved in the planning process in order to empower consumers of services.

5. At present many clinical decisions are determined by reimbursement structures, which are not always in concordance with the results of scientific research or professionally developed guidelines.

6. While developing countries may have other pressing health priorities, there is a need to encourage future planning of continence services together with promoting awareness in anticipation of the aging population.

7. There is a need for research on outcomes, not just the process of service delivery. These outcomes must be patient-focused, and evaluate the outcomes of all comers to a service (not just specific treatments for specified groups). To do this, validated audit tools are needed as well as longitudinal studies of services (e.g., nursing home admission rates).

8. There is a need for cost-effectiveness studies of a whole service and evidence on whether high quality services save on costs.

a) The needs of service users

It is only recently that the desires or needs of people with incontinence themselves have been seriously considered. With an embarrassing problem like incontinence, many have been reluctant to report or to complain when they experienced symptoms. Many do not seek help anyway, and expect little when they do. In the UK, continence was one of a series of qualitative studies into users' views on health services. Responses were mixed [90]. Some people were appreciative of the compassionate treatment they had received, but others seemed bewildered by the intricacies of getting help. A series of 14 recommendations on making services accessible and acceptable were made.

It is important not to assume that all incontinent people want or need help, and this may vary considerably between different cultures. One community study found that only half of people who identified themselves as having incontinence of urine took up the offer of a local consultation [91]. In another study, a postal questionnaire asking about urinary symptoms found that nocturnal problems caused the most bother (69% were bothered by nocturnal enuresis, 63% by nocturia). Only 50% found stress incontinence a bother, 56% were bothered by urge incontinence [92].

A community interview study found that only 15% of severely incontinent women (daily incontinence requiring protective pads most of the time) were worried about it, and 15% felt that their activities were restricted. Most seemed able to cope. Overall, 78% were not worried by their incontinence and the authors concluded that their findings "do not support the hypothesis of severe psychological effects of hidden incontinence". They therefore suggested that services should be targeted towards the minority who do find it a problem [93].

In Japan it has been found that 55% of elderly incontinent people do not consider incontinence a bother, but 15% did not go out, 10% found it difficult to go out and 10% felt that they caused bother to family and neighbours [94]. A Japanese survey of over 1,000 caregivers of elderly incontinent people in the community found that more than 80% of caregivers are female and over half were more than 60 years old. (Kitagawa, 1997) The caregivers felt that incontinence caused problems with the home getting dirty (10%); extra laundry (9%); need to wake at night (7%) and not being able to go out because of incontinence (9%). When asked what kind of government service they wanted, caregivers replied "health training" (10%); "knowledge about incontinence" (10%); and "supply of a portable toilet" (3%). Only 6% wanted the government to send them professional caregivers and 4% desired referral to a specialist doctor.

Some people seemed to cope better than others with symptoms, and some had coping strategies which were easily undermined by any suggestion that professional help was required [95]. Few people seemed prepared to take action to prevent incontinence. In France, where the state will pay for women to have up to 10 sessions of pelvic floor rehabilitation after childbirth, only 30% take up this offer.

This can create a dilemma - should health professionals attempt to persuade people who do not see incontinence as a problem that it is an abnormal condition? Is lack of bother genuine, or simply a defence against having to tackle an unpleasant problem? Does early intervention prevent later deterioration in symptoms? Does delay in treatment mean that success rates are lowered? There is scant evidence on any of these issues, or on the most acceptable way of providing help.

In a USA survey, UI was seen in 53% of homebound patients and was a leading reason for caregivers to place a family member in a nursing home [96]. The relatives of 50 patients admitted to the hospital because caregivers could no longer cope were asked which factors, if alleviated, would have enabled coping. Micturition at night, fecal incontinence and incontinence in an opposite-gender parent who needed intimate care were among the least well-tolerated problems [97].

b) The United Kingdom Continence Care model

The UK continence services have grown up over the past 2 decades without, until recently, any central planning or guidance. Local needs, interests and often personalities have driven developments. Two main models have emerged. One is a service led by a hospital consultant doctor (urologist, gynecologist or geriatrician), often focused around an urodynamic unit providing medical or surgical treatment. The other model is a nurse continence adviser-led model. The continence nurses often work in both hospital and community, and the service is focused on primary care (particularly district nurse) assessment of patients and organization of free incontinence product delivery to the home. Only recently, except in a few notable situations, have truly multidisciplinary services emerged. It is unknown if these model are effective for addressing all needs of persons with incontinence.

The Royal College of Physicians set up a multidisciplinary working party, which made a number of recommendations on continence services [98] (See Table 1). The Department of Health has identified the key elements of a continence service and strongly advised Health Authorities to implement this [99]. It is a very complex job to integrate all elements into a coherent service. Some continence services or information are targeted to a specific segment of the population, such as a project to provide continence advice to the 23 % of women in the East End of London who were Bangladeshi [100].

Table 1 : Royal College of Physicians' Recommendations for a Continence Service

The structure required to achieve these aims might include: a designated manager, an expert advisory panel and a budget to provide staff, their training and support services, and containment materials and equipment.

A continence service should include:

- a defined method of entry for patients referred by family doctors, nurses, hospital staff and patients themselves
- access to appropriate diagnostic facilities, including urodynamics and anorectal investigations
- access to medical and surgical consultants with a special interest in incontinence
- integration of incontinence services for children with other paediatric services
- attention to the wishes of patients and caregivers
- access to nurses and physiotherapists with special training in treatment modalities for incontinence
- a role for one or more specialist continence advisors in the education of the public and professionals in continence maintenance
- a policy concerning the purchasing and supply of containment materials and equipment in the community, in residential and nursing homes and in hospitals
- well defined audit and quality assurance systems.

Source Royal College of Physicians, 1995

The Department of Health in the UK has commissioned an evaluation of different models of nursing services, with and without specialist continence advisers [101]. It was found that where there is a continence nurse, incontinent people are more likely to receive targeted referral to specialists such as an urologist, and are more likely to have had investigations and to receive more appropriate treatment and care for their incontinence. These patients were also more likely to report satisfaction with the service. In most areas the continence nurse is involved in individual patient assessment, to sort out the simple problems at the primary care level and implement conservative therapy where appropriate.

c) The Israeli model – starting an integrated service

In January 1994, a national center for geriatric incontinence was established in Israel. Previously, there were very limited services and it had previously been found that 20% of older people and 53-100% of those living in institutions had urinary incontinence. Only 2% had received proper evaluation and treatment [102].

A National Center for Continence was formed that included a team of professionals (two urologists, two geriatricians, two nurses skilled in geriatrics and in home care, a social worker, a co-ordinator and a secretary) from different institutions. This allowed promotion of interdisciplinary exchange as well as maximum co-operation between the Medical Centers and the community health services. After 6 months of training, the team was ready to address the goals of the Center. After trying various education and training programs an approach which fits the healthcare system was developed. A clinic was pre-selected to be trained according to certain criteria: it must be a large clinic with at least 3 family doctors and a service population of over 20% elderly patients. A local team composed of a physician and a nurse are also pre-selected to be in charge of promotion, detection and treatment of incontinence at the clinic. Questionnaires and evaluation sheets developed by the Center were to be used. The education program included training the entire staff of the clinic, and the team received supplementary training. A new position of regional continence advisor was created. The best physician and nurse among teams in a region received additional training to be in charge of incontinence in the whole region.

This system enables professionals to approach local or regional advisors as well as to contact the Center directly, and it gives the Center feedback on the activity and success of individual clinics. Centers staff make frequent visits to the clinics, maintain contact via telephone and by a quarterly newsletter. There is also an update program every 6 months for all professionals. The Center has developed a training program in nursing homes, where mostly nursing staff and aides provide treatment.

The outcomes of this program are constantly examined. Data on patients, detection, and success rates are collected each month from the clinics and nursing homes. Results have shown that this model of training combined with consultancy back up is beneficial. Detection rates are high, and there is an average of 70% success rate for patients treated at the clinics. In the nursing homes, in addition to a surprisingly high success rate, treatment of incontinence made family members more involved with the patients' progress, saved costs on diapers and added to the prestige of the nursing home.

The Center has also set up a central clinic equipped with advanced diagnostic tools (e.g., urodynamics), and a selection of treatment options including surgery. Other activities include the development and production of effective tools intended for professional staff, telephone advisory services to healthcare providers as well as to the public, production of information brochures and audiocassettes, and promotion of awareness through lectures in the community. The Center organised the first national meeting on incontinence and conducts clinical and epidemiological trials along with basic science research. Most recently, fecal incontinence management has been included in the Center's training program and a catalogue of all products available in Israel is being completed.

A countrywide program for establishing satellite centers is currently in progress. Plans for the near future are to establish a Hotline for the public, to promote education programs in nursing and medical schools, hospitals and nursing homes and to develop guidelines for diagnosis and management of incontinence by primary healthcare staff.

d) Community continence services – is there an ideal model?

The Israeli experience suggests that, where few services exist, it is feasible and effective to stimulate effective community management of incontinence, with limited specialist back- up. There are many factors that can persuade health care planners of the importance of adequate investment in community continence services: the prevalence and the number of incontinent people is likely to increase with an aging and increasingly dependent population; many frail, disabled or elderly people are incontinent for reasons extraneous to the urinary system (such as poor mobility, an inappropriate physical environment or lack of an individualised care regime). It is often best to provide a first assessment for such individuals in their usual surroundings and to reserve hospital or clinic referral for those who do not respond to simple measures such as treatment of constipation, modifying a diuretic medication or provision of accessible toilet facilities. A number of guidelines have suggested an algorithmic, step-wise approach to assessment and treatment of incontinent people and many conservative treatments have a good success rate in primary care [2, 40, 103].

Incontinence is an expensive problem. It is likely, but as yet unproven, that more investment in prevention and early detection could prevent progression of symptoms for some people and prevent them from eventually becoming major users of resources (such as needing a nursing home place because incontinence can no longer be coped with at home). However, it is recognised that in some health care systems, such as Japan, primary health care is not well developed. In such situations primary care continence services may not be realistic.

e) Family doctors and incontinence

Family doctors are often ideally placed to delivery UI services through early detection. For example, 87% of older Australians visit their family doctor at least once per year [104]. However, many family doctors lack the necessary training, time, self-assessment tools and effective primary care strategies, knowledge or confidence to manage UI successfully.

A New Zealand study of 600 family doctors found that most respondents provided continence care, and 2.6% offered special clinics for continence promotion [105]. Fewer than half felt confident to diagnose the causes of incontinence. Confidence in managing incontinence in children was consistently lower than for other childhood problems. There was no difference by sex in confidence, although female respondents were more likely to consider management of continence care as part of a practice nurse's role and to routinely ask well women about incontinence. Most respondents (71.9%) could not remember having had any formal training in the management of incontinence either at the undergraduate or postgraduate level. Recall of postgraduate education was associated with greater levels of confidence in management of continence problems.

In a questionnaire study in the UK replies were received from 560 family doctors. They were more likely to refer men than women and younger rather than older patients with UI to a specialist. Fifty-three percent had seen 3 or more incontinent patients in the past month. Twenty-nine percent routinely ask about incontinence at well man clinics, 54% do so at well women clinics, 6% do not ask at over 7 years of routine screenings. Eighty percent would always test the urine, 60% would always send a sample for microscopy. Women and older doctors were more likely to refer and felt that the most helpful people were the community nurse, gynecologist and urologist. Only two-thirds used geriatricians or continence nurses, half use physiotherapists. The author concluded that family doctors see a lot of incontinence, and vary in how they manage it [106].

Family doctors have been shown to be successful in treating incontinence. A UK study examined assessment and treatment of 65 women, who were treated according to their type of incontinence. Those with stress incontinence were treated by pelvic muscle exercise, those with urge incontinence by bladder training and medication, and those with mixed incontinence by both. Both stress and urge, but not mixed, improved compared to controls at 12 weeks [107]. A Dutch study of 110 women reporting UI to a family physician were randomly assigned to treatment or control. Treatment was pelvic muscle exercises for stress and bladder training for urge. Patients were interviewed at 3 and 12 months, with crossover at 3 months for controls. At 3 months, 60% were dry or only slightly incontinent. Mean wet episodes were down from 27 to 7 per week. Seventy-four percent felt improved or cured and there was further slight improvement at 1 year [38].

A study in a community clinic in Israel showed that after training, family doctors detected 100 patients with UI during a period of 19 months. Mean age was 71years (range 56-89), 94 females and 6 males. Most patients (53) were detected by the physicians on direct questioning, some by nurses (29) and only 18 by self-referral. After a mean follow up of 10 months, 35 were dry and 32 significantly improved. Cure or improvement was achieved at the clinic with no involvement of urologist or gynecologist [108].

f) Multidisciplinary care

Some countries are starting to tackle problems of coordinating continence services by consulting on and agreeing to referral criteria and pathways. Others have set up multidisciplinary clinics, such as a "Pelvic Floor Clinic" where gynecologist, urologist, colorectal surgeon, physiotherapist and continence nurse work together [109]. The issue of fecal incontinence services is not included in this chapter but consideration should be given to the desirability of close co-operation where the patient has double incontinence.

There is some evidence on the effectiveness of multidisciplinary clinics. A Canadian study looked at 184 women, with a mean age of 60. Eighty-eight patients were treated and seen weekly for 6 months. Ninety-four controls were also seen at 6 months. The main interventions were pelvic muscle exercises, bladder training, and advice on fluids and the reduction of weight and smoking. Thirty-four percent of the treatment group were cured and there was a significant improvement in the amount of leakage and bladder control compared to controls. The study did not report on the outcomes in the control group [110].

An Australian study took all community referrals of those who had been incontinent for at least two months and had at least one episode in past 2 weeks to a continence clinic. Patients were randomised to conservative treatment or control, with a crossover design. Patients were asked subjective questions about embarrassment, odor, depression, family relationships, isolation and laundry on a 4-point scale ranging from no effect to major effect upon life. The questionnaire was completed at the start, and at 2, 4, 8, and 12 months. Seventy-eight patients entered the study; 87% improved with treatment (41% controls also improved). Fifty-two percent were moderately or severely embarrassed at the start of the study period; only 17% were at 4 months. Depression decreased from 49% to 22% and isolation from 28% to 12%. Odor and extra laundry also decreased. All benefits were maintained at 12 months. Controls did not improve on these items until crossed over to active treatment, despite feeling better. The authors conclude that conservative treatment in a multidisciplinary community clinic improves continence and well being [111]

g) Other specialists practitioners

One study found that a nurse was competent to assess and manage community patients after 3 weeks of training [112]. Patients received 4 sessions of exercises and bladder training. Sixty-eight percent of women were subjectively cured or improved after nursing intervention, compared to 5% of controls. Only 22 of 86 men were suitable for treatment by the nurse, 17 were cured or improved (no controls improved). They concluded that many incontinent people could be effectively managed by a nurse with limited additional training, reserving specialist medical help for resistant cases. These results seem to be sustained in the long term. In a follow up study 89% were followed up 4 years later. 69% had maintained or improved their continence status. Improvement was strongly associated with continuing pelvic floor exercises for more than a year.

In a Canadian study, 421 subjects were assessed by a nurse and then randomised to treatment or control. The treatment group improved in voiding frequency and wet episodes as compared to the control group [37]. Another Canadian study found that interventions were effective in reducing incontinence and patients were satisfied and felt that they had received control over the problem [113].

In UK, a new mode of service delivery that was dependent on specially trained CNPs was shown to be effective in reducing urinary symptoms and led to high levels of patient satisfaction [114].

A recent study in the USA demonstrated significantly improved outcomes for three clinical problems; urinary incontinence, depression and pressure ulcers when advanced practice gerontological nurses (APNs) worked with nursing home (NH) staff to implement scientifically based protocols [115]. In addition to working with NHs to provide resident evaluation as physician extenders, this research indicates that APNs can be an effective link between current research based knowledge about clinical problems and NH staff. This study also showed that consistent educational efforts with staff and residents demonstrated that interventions could improve or stabilize the level of UI in many persons.

In some countries, physical therapists (PTs) have also developed a specialized practice with incontinent clients. In France all women are entitled to up to 10 sessions of pelvic floor rehabilitation physiotherapy, paid for by the government, after childbirth. In Australia, Scandinavia and the UK, research on pelvic floor exercise has been led by PTs. However, there is a lack of consensus as to best practice for incontinence. In a postal survey of British PTs found that many were providing a specialized service. Gynecologists were the most common source of referral. The majority said physiotherapy was first line of treatment. Pelvic floor muscle exercises and electrical stimulation were the most used modalities. However, there was little consensus about optimum treatment regimes and a wide variety in the details of therapies used [26, 29].

h) Childhood enuresis services

Very few countries have well-developed services for nocturnal enuresis in childhood. These are seldom well integrated with adult continence services, although some continence nurses do run enuresis clinics. Most clinics are the responsibility of pediatric, school health or psychology services.

i) Services in developing nations

Continence services are a relative luxury, to which countries with a low per capita income are unlikely to devote scarce resources until more “life and death” issues are addressed. For example, in Brazil, priorities for their health budget are childhood immunizations, AIDS/STDs, basic sanitation, healthy environment and literacy to help with the problem of street children. The Mission Statement of the Pan American Health Organization is “to promote the full development and utilization of human capabilities through health promotion activities and stronger intersectoral and community action to improve the living conditions of the most socially neglected groups.” In such circumstances it is unrealistic to expect a major priority given to a subject such as UI. The one instance where UI has become a recognised problem in developing countries is incontinence secondary to obstetric fistula.

Ethiopia’s Health Minister has stressed the need to develop rural health services to reduce the incidence of fistula and to have first time mothers examined by Traditional Birth Attendants (TBAs). It is planned that TBAs will be trained to identify high-risk women, and thereby divert expenditure from high cost doctors and urban health services to training community health workers and health education. Attitudes on female circumcision, contraception and women’s health, which are often decided by their husbands, obviously have much wider implications than just continence care.

A demonstration project in northern Nigeria has reported training obstetric fistula patients to act as peer educators to help prevent vesico-vaginal fistula [116]. The concept of peer health educators has been used in many developing countries. Given local traditions of seclusion of women, only their peers may have access to women of childbearing years.

j) Financial issues and funding of services

It seems that the major share of expenditure goes toward additional hospital admissions, longer hospital stays, home care, and routine care expenses rather than toward therapeutic interventions. It is not known what impact might be made by diverting a portion of current expenditure to education of professionals or the public, or to investigation and cure.

There are always decisions to be made on how to allocate scarce resources, for instance between hospital and community services; high tech and conservative treatments; cure and products to support people with intractable incontinence in their own homes. Cure should always be the aim where this is feasible, and no continence service should merely manage the incontinence without individual assessment, care planning and an attempt to improve continence. Where there is one overall mechanism for planning the whole service, there is the potential for rational allocation of resources and a seamless service. Where the service is fragmented and the responsibility of several different agencies, there is the danger of competition for funds, or shifting responsibility between budgets without actually benefiting the patient or saving on costs.

Funding arrangements will also mould the configuration of a service. For instance, in France, where postnatal pelvic exercises are reimbursed, many PTs have developed a continence expertise; in the USA, where it is more difficult to be reimbursed, fewer PTs are expert in this area. In the USA in 2001, the Commission on Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration, which administers Medicare, the insurer of the disabled and elderly, recommended biofeedback assisted pelvic muscle exercises and pelvic floor electrical stimulation as a reimbursable service. It is important that professionals involved in continence care make funders aware of optimum clinical efficacy, and how funding arrangements can potentially distort clinical decisions.

k) Cost-effectiveness of continence services

It has sometimes been argued that good continence services may ultimately save on costs. The evidence for this is scant and difficult to measure. A survey of 49 homebound patients with indwelling catheters in Israel showed that one year after the intervention of a trained team, there was a significant reduction in emergency calls, hospitalisation rate and complication rate due to proper management [117].

Provision of a service can increase costs when many people who were not previously treated seek help. Whether the cost per case can be decreased by better management remains to be proven, as does the cost implication of prevention of symptom progression by early treatment. However, the ultimate aim of services should be to improve quality of life rather than simply minimize costs.

l) Protocols and guidelines

There have been several attempts to improve clinical practice by issuing centrally produced guidelines. The USA has done this on the largest scale [2,40,103,118]. From the first Urinary Incontinence in Adults guideline issued in 1992, and the second completely re-worked edition in 1996, over 3.5 million copies of the three documents (detailed report, summary and patient guide) have been issued in English and Spanish, 58% to consumers. However, it is not clear that a paper guideline always reaches the intended target. Only 17% of physicians had seen or read the 1992 AHCPR guidelines [17]. A huge effort and expense may not result in a change in behaviour, and research on effective dissemination and implementation of research findings should be a priority. This effort is now being further developed by the USA National Institutes of Health (www.nih.gov) by way of computer-based patient assessment documentation linked to the guidelines. By linking in to a server, health practitioners can access online information relevant to the individual patient under assessment.

The USA has also attempted to influence and improve clinical practice in nursing homes by statutory regulation. The 1987 Omnibus Budget Reconciliation Act made it a statutory requirement that nursing homes maintain as normal a level of bladder function as possible. To ensure that this happens, the CMS issued a minimum data set (MDS) to be completed for all nursing home residents. The MDS includes items about bladder function, which, if positive, should trigger a more detailed assessment of bladder function.

The NAFC developed a Blueprint for Continence Care for Assisted Living Facilities (ALFs) in the USA. The Blueprint addresses gaps between intentions and practices and discusses assessment of residents, management of their conditions and training of caregivers [119].

The UK Department of Health has commissioned a multidisciplinary panel of experts to draw up recommendations on outcome indicators by which to measure the performance of continence services [120]. The effectiveness of the indicators has yet to be evaluated.

B. WORLD WIDE ORGANIZATIONS

1. BACKGROUND

The International Continence Society, in setting up a Continence Promotion Committee, and in hosting this International Consultation of Incontinence (1998 & 2001), has recognised a broader responsibility than its former role as a forum for scientific research. Many in the scientific and medical community have also been active in developing national policies services and organizations, in teaching professionals and in public awareness activities. Although it may not be practical to develop global and uniform strategies for continence promotion and public awareness, much can be learned from the positive and negative experiences of other organizations in other countries.

Continence promotion is a most challenging endeavour. Although the ratio between affected patient populations and continence organizations funding has not been formally studied, anecdotal information suggests that fundraising for continence programs is among the most difficult of medical problems for which to obtain funding. In view of all these challenges, the proliferation of new continence organizations, especially in the Far East, is a validation of both the need for continence promotion and the dedication of those who have recognized and are addressing this need.

2. QUALITY OF DATA *(Level of Evidence - 4)*

There is a paucity of published work on the formation of national organizations that target consumers or the general public. Appendix 1 gives the contact details for national continence organizations. A professional or medical organization is listed if there is no organization that targets the lay public in that country. The countries where there is an organization generally seem to have greater public and professional awareness about continence and more educational activity and materials available, although the direction for causation in this relationship is not always clear. The countries where there is more interest are more likely to develop an organization. A CD-ROM on how to set up a continence organization is available from the Society for Continence Singapore.

3. CONCLUSIONS -

(Grade of Recommendations - D)

1. A worldwide association of continence organizations, under the auspices of the Continence Promotion Committee of the International Continence Society should be explored. This will create a central co-ordinating body for continence activity to be encouraged and should be a catalyst in countries where there has as yet been little development of services, education and awareness. This Worldwide collaboration must spearhead the formation of a "World Bladder Health Day".
2. Resources for promoting continence are scarce, especially in proportion to the magnitude of the problem. Unique, creative solutions must be found to maximize all available resources.
3. Free exchange of continence information and materials between countries should be encouraged. This can be co-ordinated via the Continence Promotion Committee (CPC) of the International Continence Society and the CONTInet Internet site. In order to accomplish this task, funding for an experienced executive director for the CPC should be a priority.
4. A "media bank" should be created. This "bank" would contain medical art, illustrations, and animations related to incontinence (a set for consumer education and a set for medical education), which could be used by any organization, eliminating the costs all organizations generate when creating educational materials.
5. A data bank should be established on the CONTInet Internet site and formatted for standardized reporting of program launches worldwide. This "experience bank" database would create an avenue for fast and efficient experience exchange.
6. "Information modules" with ICS-approved language should be created (and posted on CONTInet) to help organizations communicate clear, standardized information in their educational material for the general public.
7. Organizations must undertake market research to better understand the needs of people with incontinence, so as to set their own agenda and priorities rather than being led by the availability of funding.
8. Adequate funding will often involve commercial collaboration, but attention must be given to ethical considerations, in particular avoiding direct product endorsement.

- **Summary of Current International Organizations**

National organizations, which promote continence, are as diverse as the cultures they serve. They represent a wide diversity of models, including consumer-led, company sponsored, professionals only, and organizations which have deliberately set about trying to bring together all relevant stakeholders in a relatively democratic set-up. In every part of the world these organizations play a dynamic role in building both public and professional awareness of this under-served and under-reported condition. Most continence organizations are poorly capitalized, being either under or unfunded (i.e., run by volunteers) and are held together initially by either a dedicated patient advocate or an energized health professional. Yet, despite this limitation, these organizations often provide their country with the first wake-up call that incontinence is common.

Although the exact founding date of the first continence organization is not known, none have been in existence longer than three decades. Even so, the wealth of experience, the creativity of endeavours which have been tried, and the method in which older organizations are evolving into established foundations are all worth studying. However, the challenges of cross cultural communications, language barriers, and the costs of travelling to international meetings make information sharing a unique challenge.

Each of the organizations listed in Appendix 1 were sent a survey requesting general information about the organization. Organizations that primarily target the general public generally do not participate in educating professionals. Those countries where a consumer-based organization does not exist do engage in educating professionals as well as raising the awareness of incontinence to the population in general. Except for the USA, most countries responded that incontinence services are paid through national health insurance plans. The USA has a combination of government and private insurance. In those countries that have consumer-based Continence organizations, there are national public awareness campaigns about USA programs (e.g., has a designated "Bladder Health Week" every fall). Organizations were quizzed about the origin of funding or financial support. Most receive funding from members or charitable donations. Other sources included lottery funds (Great Britain) or corporations. It was generally felt that media coverage in these countries is inadequate. Only the USA indicated that there was a national organization that addresses fecal incontinence.

In 1994, the Singapore Continence Society set up "CONTInet", an electronic network on the World Wide Web [121]. This service will eventually develop an index system to facilitate rapid easy communication of information between organizations and individuals. The initial focus has been networking of continence organizations and internal International Continence

Society business, but there is also the facility for announcements of meetings, publication of abstracts, rapid sharing of resources and teaching materials and co-ordination of multi-centre research. The CONTInet can be found at: http://www.org.sg/continet/, or at: http://www.dpa.org.sg/continet.

While there is little data on the outcomes of the use of organizations to change consumers' views and awareness of incontinence, there is one model that indicates coordination of countries may be a more efficient use of resources and time. The Asia Pacific Continence Advisory Board (APCAB) was established with a mission to develop "Continence Promotion" programs that work together with healthcare providers and the general public to develop strategies to increase awareness and reduce the social burden of urinary incontinence in the Asia Pacific Rim. APCAB member countries are the following: Thailand, Korea, China, Hong Kong, Taiwan, Malaysia, Indonesia, India, Philippines, Singapore and Pakistan. APCAB's secretariat is under the administration of Society for Continence Singapore (SFCS) since its formation in 1998. APCAB conducted its first Asia-wide prevalence survey on "Overactive Bladder" to obtain epidemiological data in the respective countries [122]. The SFCS coordinated this project and successfully completed the study in six months. By the end of year 2000, SFCS helped nine out of these eleven countries to form their own continence organizations.

The Committee would like to thank Nancy Mueller, Executive Director, National Association for Continence and Carole Mertz for their review of this chapter.

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APPENDIX 1

INTERNATIONAL CONTINENCE ORGANIZATIONS

Note: Only organizations, which have their major focus on continence for the consumer/general public, are included here. Professional organizations are listed if they are the only formal consumer/lay public based organization in a particular country.

AUSTRALIA

Continence Foundation of Australia Ltd
AMA House, 293 Royal Parade
Parkville, Victoria 3052
Tel: 61 3 93472522 Fax: 61 3 93472533
website: info@contfound.org.au

CANADA

The Canadian Continence Foundation
2100 Marlowe Ave, Suite 350
Montreal, Quebec H4A 3L5
Tel: (1) 514 488-8379 Fax: (1) 514 488-1379
Website: www.continence-fdn.ca

GERMANY

Gesellschaft fur Inkontinenzhilfe e.V. (GIH)
Friedrich-Ebert-Strasse 124
34119 Kassel
Tel: (49) 0561 780604 Fax: (49) 561 776770
Website: http://www.gih.de

HONG KONG

Hong Kong Continence Society
Room 214, 2/F Tung Ying Bldg
100 Nathan Road
Hong Kong
Tel: 852 2311 2218 Fax: 852 2311 2633
Email: kwokfook@netvigator.com

INDIA

Indian Continence Foundation
c/o Bangalore Kidney Foundation
CA6, 11th Cross, 15th Main Padmanabhanagar
Bangalore 560 010
Tel: 91 80669 0084/6691145
Fax: 91 80669 2466
Website: www.indiancontinencefoundation.org

INDONESIA

Indonesian Continence Society
Unit Urology, University of Diponegoro
Dr Kariadi Hospital
Jl. Dr Sutomo No 16 Semarang
Indonesia
Tel: 62 24 310152
Email: drrudi@indosat.net.id

ISRAEL

National Center for Continence
Rambam Medical Centre, POB-9602 Haifa 31096
Tel: 972-4-8543197 Fax: 972-4-8542883
Email: ig054@hotmail.com

JAPAN

Japan Continence Action Society
Continence Centre
103 Juri Heim, 1-4-2 Zenpukuzi Suginami-Ku
Tokyo, 167 0041
Tel: 81 03 3301 3860 Fax: 81 03 3301 3587
Website: http://www.shodouka.com/

KOREA

Korea Continence Foundation
Department of Urology, Dong-A
University Hospital, 3 Ga-1
Dongdaeshin-dong, Seo-Gu
Pusan City 602-715
Tel: 82 51 240 5446 Fax: 82 51 253 0591
Email: hykwon@seunghak.donga.ac.kr

Hee Seon, Yu, RN
7-206, 3-GA, Shinheung-Dong
Jung-gu Inchon, 400-103
Korea
Tel: 82 32 890 2365 Fax: 82 32 890 2363
Email: forever@inha.com

Sun Yeon Hwang
Hyundae Apt 103-1701, Dadae 2 dong, Sahagu
Pusan, S-Korea
Tel: 80 051 240 5766 Fax: 80 051 255 9286
Email: HSY1701@damc.or.kr

MALAYSIA
Continence Foundation (Malaysia)
c/o University Hospital, Lembah Pantai
Kuala Lumpur 59100
Tele: 603 7956 4422 Fax: 603 758 6003
Email: lohcs@medicine.med.um.edu.my

NEW ZEALAND
New Zealand Continence Assn Inc
41 Pembroke Street
Hamilton, New Zealand
Tel: 64 7 834 3528 Fax: 64 7 834 3532
Website: www.continence.org.nz

NORWAY
NOFUS (Norwegian Society for Patients with Urologic Diseases)
Linjeveien 178, N-1400 Ski
Norway
Tel: 47 64 87 28 45 Fax: 47 64 87 42 08
Email siralf@sensewave.com

PHILIPPINES
Continence Foundation of the Philippines
319 M.O.L.B. Bldg
Katipunan Road
Loyola Hts
Quezon City, Philippines
Tel: (63)-2-4333602 Fax: (63)-2-4333602
Website: continence99@yahhoo.com

SINGAPORE
Society for Continence (Singapore)
c/o Department of Urology
Changi General Hospital
2 Simei Street 3
Singapore 529889
Tel: (65) 787 0337 Fax: (65) 5881723
Website: http://sfcs.org.sg

SWEDEN
SWEDISH UROTHERAPISTS
Nordensioldsgatan 10, S-418 04
Goteborg
Tel: 46 31 50 26 89 Fax: 46 31 53 68 32
Email: birgtha.lindehall@vgregion.se

TAIWAN
TAIWAN CONTINENCE SOCIETY
Department of Urology
Taipei Medical College Hospital
(TMCH)
No. 250 Wu-Hsin St.,
Taipei, Taiwan
Tel: + 886 2 2737 5076 Fax: + 886 2 273 77470
Email: hansun@mail.tmc.edu.tw

UNITED KINGDOM
THE CONTINENCE FOUNDATION, UK
307 Hatton Square
16 Baldwin Gardens
London EC1 N 7RJ
Tel: (44) 207 404 6875 Fax: (44) 207 404 6876
http://www.continence.foundation@dial.pipex.com

Enuresis Resource and Information Centre (ERIC)
34 Old School House, Britannia Road
Kingswood, Bristol BS15 2DB
Tel: (44) 117 960 3060 Fax: (44) 117 960 0401
Website: www.eric.org.uk

***In*contact**
United House, North Road
London N79DP
Tel: (44) 207 700 7035 Fax: (44) 207 700 7045
Website: www.incontact.demon.co.uk/

UNITED STATES OF AMERICA
American Foundation for Urologic Disease
Bladder Health Council
1128 North Charles Street
Baltimore, Maryland 21201-5559
Tel: 410-468-1800 Fax: 410 468 1808
Website: www.afud.org

International Foundation for Functional Gastrointestinal Disorders
P O Box 170864
Milwaukee WI 53217-8076
Tel: 414 964 1799 Fax: 414 964 7176
Website: www.iffgd.org

National Association for Continence
P O Box 8306,
Spartanburg, SC 29305-8310
Tel: 864 579 7900 Fax: 864 579 7902
Website: www.nafc.org

Simon Foundation for Continence
P O Box 815
Wilmette Illinois 60091
Tel: (1) 847 864 3913 Fax: (1) 847 864 9758
Website: www.simonfoundation.org