



**Brian Buckley, Brid Kennedy and Mary Murphy describe a new initiative aimed at improving awareness of continence problems**

# Barriers to effective care of incontinence

**INCONTINENCE HAS BEEN DEFINED** as the demonstrable involuntary loss of urine or faeces.<sup>1</sup> It occurs in all ages for many different reasons. For some, incontinence is an occasional slight leakage from bladder, or bowel, or both. For others it is an absolute inability to control voiding. Such bladder and bowel control difficulties are associated with very many and varied conditions.

The prevalence of incontinence in any population has proven to be difficult to establish; definitions between studies vary, as do the populations surveyed, and the extent of under-reporting is unclear. For example, prevalence estimates for any urinary incontinence (UI) range from 5% in women over 15 years of age in Belgium, to 69% in women over 19 in Wales.<sup>2,3</sup> Commonly used figures for 'regular' UI are those resulting from a 1995 Royal College of Physicians study.

The study found that 8.75% of women under 65, 15% of women over 65, 3% of men under 65, and 8.5% of men over 65 suffered from UI.<sup>4</sup> More recent research resulted in higher estimates for UI 'several times a month or more often'. The research found that 8.9% of men over 40 and 20.2% of women over 40 suffered from UI.<sup>5</sup> In addition, it is estimated that 1% to 2% of adults experience bedwet-

ting, 1% of adults experience significant faecal incontinence and 5%-10% of 5-14-year olds are affected by bedwetting, daytime wetting or soiling.<sup>6</sup>

There is little doubt that many people affected by regular incontinence as well as other bladder or bowel control problems, which can result in occasional incontinence, are anxious to conceal the problem, and reluctant to discuss it.<sup>7-9</sup>

In the population as a whole, a majority of those who are incontinent do not seek professional help.<sup>10</sup> In eight separate UK studies the average figure for those affected by incontinence who seek help is only 34.3%.<sup>11</sup> Research in Ireland showed that 60% of people aged 40 or over with bladder problems have never discussed these problems with a doctor or nurse. The research also showed that 56% of people aged over 75 who were incontinent had not told their GP.<sup>12-13</sup>

Failure to seek help can result from embarrassment, or a belief that incontinence is normal, especially in women following childbirth, or in both sexes after a certain age. Poor awareness of treatment options promotes a feeling in many sufferers that nothing can be done, or that surgery is an inevitable result.<sup>7,14</sup>



The stigma associated with incontinence sets it apart from most other health problems, and will inevitably influence behaviours. This taboo means public awareness and understanding of both incontinence and available treatment remain poor.

#### **Awareness and support project**

The Continence Awareness and Support Project (CASP) is a cross-border initiative developed by four organisations: Incontact (Action on Incontinence); the Sperrin Lakeland Health and Social Care Trust and the Foyle Health and Social Services Trust in Northern Ireland; and the Donegal region of the HSE Western Area. The project is supported by Co-operation and Working Together (CAWT) and funded by the European Union INTERREG IIIA programme. The project's objectives include the identification of gaps in service and information provision. The promotion of improved public and professional awareness of continence problems aims to facilitate understanding and prevention, and establish more effective professional practice with regard to case-seeking and referral.

#### **Methods**

A one-day workshop was held to canvas the views of a wide variety of people in relation to continence problems and services. The aim was to form, through discussion and consensus, an overview of issues which affect awareness and understanding of incontinence and of the relevant treatments and services available, gaps in service and information provision, and opportunities for improvement and of barriers to help-seeking.

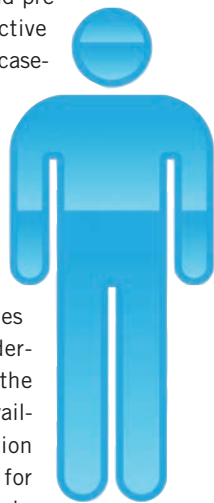
After introductory presentations which outlined the background and aims of CASP, the attendees were split into focus groups which focused on three age-groups: children (0-18), adults (18-65) and older people (65+). Guided by independent facilitators, each group then discussed continence issues relating to each age group.

In order to ensure consistency between the three groups, discussion was guided by a provided list of topics based upon existing literature which included: types and causes of continence problems, service needs, barriers to seeking help, information needs, potential avenues for delivery of awareness, and information materials or interventions.

At the end of the focus group, a summary of the discussion was presented to participants. The summaries of the three focus groups were then presented to the attendees in the last session of the day and discussed further.

Data analysis followed the principles of framework analysis, and involved five key stages<sup>15</sup>:

- Familiarisation (preliminary examination of all data)
- Developing thematic framework
- Indexing the material
- Charting
- Mapping and interpretation to inform the key objectives of the research (producing an overall picture relating to study objectives, issues raised by participants and other relevant research and theoretical perspectives).



#### **Results**

The event was attended by 60 people; 40 attendees were healthcare professionals. Both healthcare practitioners and managers were included, representing a wide variety of disciplines, including continence specialists, obstetrics and gynaecology, midwifery, physiotherapy, occupational therapy, district and public health nursing, social work, paediatrics, etc.

Twenty delegates attended from the education, community and voluntary sectors, including patients and carers, as well as consumer advocates representing a variety of interest groups: primary education, community groups, women's groups, older people's organisations and a number of disability organisations.

Many issues affecting access to continence services were raised in the focus groups including:

- Embarrassment
- A belief that incontinence was normal, especially in women following childbirth or in both sexes after a certain age
- Poor awareness of services and of treatment options
- A feeling that nothing could be done or that surgery was inevitable. In addition, other issues were raised which are less well-represented in the literature.

#### **Barriers to help-seeking**

Regardless of the focus age groups studied, each group cited poor awareness of services as a primary reason for failure to seek professional help for continence problems.

It was reported that patients and carers were not sure who to ask for help, and were worried that they did not know what would be involved for patients if they sought help, since they had little knowledge about typical pathways of care.

The acceptance of incontinence as inevitable was considered to be reinforced if there was a precedent of incontinence in the family. Less familiar issues also emerged. Doubts were reported to exist in some people of all ages as to whether incontinence is really a medical problem at all, or whether it is a sufficiently serious medical problem for those affected to 'waste the doctor's time'.

Self-blame was also reported amongst women who had not complied with pelvic floor muscle exercises recommended in antenatal and postnatal education and who had subsequently developed incontinence.

Increasing perceived acceptability of incontinence in some quarters was also cited as a reason for not seeking help. The promotion of 'pull-ups' for enuresis in older children and of pads for bladder weakness in women through television advertising, was seen as 'normalising' incontinence.

Incontinence in the context of disability was reported as a particular problem: adults with disabilities reported that incontinence was frequently assumed by both professionals and patients to be an inevitable aspect of their disability, and not properly investigated; parents reported receiving mixed messages from professionals regarding appropriate



expectations with regard to continence in children with physical or learning disabilities – with the result that on occasion training and education was left too late.

#### Service-related issues

Despite increasing availability of self-referral in many areas of healthcare, GPs were regarded by most patients, carers, and professionals as being the likely first contact for anyone affected by incontinence, since they are seen as gatekeepers of healthcare services.

Yet several factors were identified as problematic: embarrassment was reported as preventing patients from citing incontinence as the primary reason for their visit to the GP, and time restrictions in consultations meant that the subject was never broached.

Some GPs were reportedly unwilling to discuss incontinence when patients did raise the issue; GPs were reportedly either unaware of local continence services or unwilling to refer, preferring to refer to urologists or gynaecologists, when a referral to a continence nurse specialist may have been more appropriate.

Particular problems were identified in the area of children's services, especially the transition from children's services to adult services. Many products and services were felt to be not 'age-appropriate'; products and services for younger children were often provided to older children inappropriately and vice versa and the transition from children's services to adult services was characterised by a period of loss of service, loss of continuity of care and poor provision of information regarding changing pathways of care.

#### School-based issues

Schools were reported as being both sources of problems associated with incontinence and potential avenues for improvement.

Bullying at school was cited as both a cause and a result of incontinence problems. For children with disabilities and associated continence problems, the school environment presented a range of difficulties. Often, appropriate facilities were not available for toileting; a lack of clarity was reported regarding the responsibilities of classroom and care assistants for children with disabilities when it came to incontinence and intimate care. The result was often containment devices, where intermittent catheterisation or prompted voiding may have been more healthy.

At the same time, a feeling amongst education professionals was expressed that an opportunity exists in schools for continence education within the context of social and sexual education.

#### Summary

This was a relatively rare opportunity for a broad range of stakeholders to discuss issues affecting the awareness, understanding, treatment and management of incontinence. The attendees reiterated some of the issues identified in the literature relating to the accessing of relevant services amongst those affected by incontinence. In addition, some less commonly expressed issues were identified, including:


- Concerns about confidentiality in GP surgeries and about discussing incontinence with longstanding family GPs
- A perception that incontinence is not a medical problem
- Self-blame because of non-adherence to pelvic floor muscle exercises recommended in ante-natal and post-natal classes

- Difficulties accessing services through GPs
- Normalisation of incontinence through television advertising of products
- Acceptability or inevitability of incontinence in disability difficulties accessing services through GPs
- Age-appropriateness of children's services and products
- Difficulties associated with the transition from children's to adult services
- Difficulties and opportunities associated with the school environment and incontinence.

#### Implications for service delivery

It is hoped that the discussion and consensus reached in the event will inform the development of initiatives which will improve the delivery and uptake of continence services in the north-west and elsewhere.

Increased public awareness would be of benefit in relation to what constitutes appropriate help-seeking among the public in general and in postnatal contexts, in older people and in disability in particular.

Amongst healthcare professionals, in addition to increased clarity with regard to appropriate referral and proper assessment (especially among people with disabilities), a greater emphasis on case-finding may be of benefit. Routine inquiries about continence status, especially among at-risk groups, might serve to mitigate the barriers to help-seeking which result from stigma and embarrassment. 

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