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and Social Care Trust**

# **Report on the Evaluation of the Cross Border Continence Awareness and Support Project (CASP)**

**Anna Edwards**

**January 2008**

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Thank you to all the Project Board members who gave their time to this evaluation during the planning stages and in providing rich information to assist in this evaluation. We also thank the consumers and professionals who managed to fit telephone interviews into their busy schedules. Finally, particular thanks to Mary Murphy (Project Manager) for all her efforts in organising the smooth running of this evaluation.

### **Project Board members**

Brian Buckley (CHAIR)	Chairman, Incontact (Action on Incontinence) and Research Fellow, Department of General Practice, National University of Ireland, Galway
Brendan Duffy	Community Services Manager, SLT/ WHSCT
Brid Kennedy	Physiotherapist Manager, HSE WEST
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Frances McGinley	Continence Advisor, Donegal PCCC, HSE West
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### **In Attendance**

Mary Murphy	CASP Project manager, CAWT
Diarmuid O'Donnell	Executive Officer, CAWT
Brigid McGinty	Programme manager, CAWT

## EXECUTIVE SUMMARY

This report is the result of an independent external evaluation of the Continence Awareness and Support Project (CASP) initiated in January 2005. CASP was initiated by the Cooperation and Working Together (CAWT) Physical and Sensory Disability Steering Group. The Project Board comprised representatives from the Western Health and Social Care Trust, Donegal representatives from the HSE, representatives of the MS Society and the United Kingdom based patient support group Incontact. Incontinence affects up to one in four people during their lives (Landefeld, 2007)<sup>1</sup> and the majority of those affected do not seek professional help (Hunnskaar et al., 2005)<sup>2</sup>. Continence problems have been shown to have a significant psychological, emotional and social impact on individuals, their families, partners and children (Buckley et al., 2007)<sup>3</sup>. The Project aimed to promote public and professional awareness, map service provision and provide information and support regarding continence services.

The impact of the Project on professional awareness of continence issues was demonstrated by the following:

- The workshop for consumers and professionals held in November 2006 enabled discussion about the stigmatised and emotive topic of incontinence and its incidence and impact.
- Difficulties in the provision of continence services for a number of groups were identified at the workshop (Buckley, Kennedy & Murphy, 2007<sup>4</sup>). These include people with disabilities; physical and sensory and intellectual disabilities. It was reported that incontinence is often accepted as an inevitable part of having a disability and was perceived as not always fully investigated by professionals.

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<sup>1</sup> Landefeld, C.S. (2007). State-of-the-Science Conference on Continence, available [www.nih.gov/news](http://www.nih.gov/news)

<sup>2</sup> Hunnskaar, S., Burgio, K., Clark, A., (2005) Epidemiology of urinary and faecal incontinence and pelvic organ prolapse. In Abrams, P., Cardozo, I, Khoury, S & Wein, A., (Eds.) Incontinence: 3<sup>rd</sup> International Consultation on Incontinence. International Continence Society, Bristol, Montreal.

<sup>3</sup> Buckley, B., Wagg, A., & Winder, A., (2007). Emotional Well-being in Faecal & Urinary Incontinence, *Continence UK*, 1 (1) 66-69.

<sup>4</sup> Buckley, B., Kennedy, B., & Murphy, M., (2007). Barriers to effective care of incontinence. *Forum: Clinical Review*, March, 51-54 (Appendix 7.4?????).

Particular problems were identified with regard to continence services for children with disabilities including mixed messages from professionals about expectations regarding continence management. At the workshop, it was raised that there appeared to be a lack of clarity regarding the responsibility of special needs assistants in relation to continence care within schools. It was also raised that for some children there may be an over dependence of containment products, rather than thorough continence assessment, treatment and management.

- There is a need to address gaps in services, for example, preventative group sessions for post natal women.
- The Project acted as a catalyst for other initiatives. For example, in December 2007, 69 Special Needs Assistants (SNA) attended evening training given by HSE - West Health Promotion and there is demand for training from 80 more SNA's. An article on continence is to be included in the School Journal for distribution in secondary schools in the North West with a view to extending this nationally.
- Resource folders for professionals were developed ,500 were widely distributed and 500 more were in production at the time of the evaluation. Professionals in residential settings in particular were appreciative of this information.
- Professional networks on a cross border and multi-disciplinary basis were established, for example a joint forum took place in January 2008 in Dundalk between the Irish Continence Interest Group and the Northern Ireland group and joint cross border training plans have been developed, for example for physiotherapists.

In terms of public awareness, over thirty visits were carried out by the Project to community and voluntary groups and there is clear demand for this service to continue. Feedback from consumers and professionals was that the relaxed and informal atmosphere of the talks was effective in reducing stigma and encouraging people to talk. The Project identified that although there is a perception that the stigma of

incontinence is gradually eroding, for example with the provision of national media campaigns such as National Bladder Week, a number of barriers remain:

- There is reluctance from the media e.g. local radio to give adequate coverage to continence issues.
- Barriers reported among professionals included workload and lack of resources. It was pointed out that there is no business incentive for GPs, who are the gatekeepers for these services, to refer to continence clinics because continence is not included in rewarded business targets unlike referrals for cancer screening.
- Most fundamentally, there is evidence that consumers are reluctant to approach a continence labelled service. As a professional commented: "Taboo plays a part in non-attendance at appointments; people are embarrassed and anxious and while they don't mind making the appointment with the GP, they don't turn up at the continence clinic.'
- Consumers may be more likely to access services under a general health service dealing with general health issues, such as through Public Health Nurses and Primary Care Nurses who do not specifically carry a continence label.

Issues for consideration to sustain and develop the work include the following:

- Funding of a post or posts, for example Paediatric Continence Advisor, Physical & Sensory Continence Advisor, Director of Continence Services in line with best practice outlined by the Department of Health, UK<sup>5</sup>.
- There is a need to lobby the commissioning bodies in the health services to acknowledge the importance of continence services and develop a cross border approach.
- Continue to develop a training strategy and business plans which will standardise training, enable updates, and extend training to GPs and professionals in allied health, social care and those working in education.
- Continue to develop consumer information in conjunction with voluntary and support agencies for the general population. Information is also required which is accessible to those with literacy problems, physical and sensory disabilities,

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<sup>5</sup> Department of Health (2000). Good Practice in Continence Services.

intellectual and mental health disabilities as recommended by the National Institute of Health and Clinical Excellence (2007)<sup>6</sup> guidelines on the management of faecal incontinence.

- The Resource packs could be updated and their use evaluated at a later date to assess their impact. Suggestions for inclusion included a list of aids and appliances available at subsidised rates, and updates on treatments. A need for information for teachers and users themselves was highlighted.
- Develop and deliver preventative group exercise classes for post natal women on a cross border basis

Learning for future projects undertaken by the CAWT partner organisations includes:

- Establishment of the Board prior to the start of the Project and before employment of the Project Manager.
- Timely training in a project management system such as PRINCE2.
- Support with clarification of the Project objectives and measurable outcomes and targets.
- Reminder of group processes and stages in group development i.e. norming, storming, performing and adjourning.
- Employment of a trained facilitator could help to make initial meetings more effective.

In conclusion, the evaluation revealed encouraging and positive feedback for the Project overall and the need to continue and extend this work was emphasised by professionals and consumers.

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<sup>6</sup> NICE (June, 2007). The Management of Faecal Incontinence in Adults, available [www.nice.org.uk](http://www.nice.org.uk)

# 1 INTRODUCTION

## 1.1 Background to the Project

Incontinence can be defined as the involuntary loss of urine and or faeces (Abrams et al., 2002)<sup>7</sup> and is a relatively prevalent but under-researched problem. Incontinence is not an illness but a symptom of a number of different conditions. There are several types of incontinence but in general, difficulties with continence affect the practical and psychological functioning of a diverse group of people of all ages. There is a paucity of data on the prevalence of incontinence owing to a variety of definitions used by health professionals and because these problems are under-reported. Incontinence is a stigmatised condition and the majority of those affected do not seek professional help (Hunnskaar et al., 2005)<sup>8</sup>. Prevalence estimates suggest that 20.2% women and 8.9% men have experienced urinary incontinence (Perry, 2000)<sup>9</sup>. In the U.S., Landefeld (2007)<sup>10</sup> has suggested that one in four will experience continence problems during their lives. Continence problems have been demonstrated to have a significant impact on individuals and their families, partners and children. Chiverton (1996)<sup>11</sup>, for example found a higher incidence of depression in women with urinary incontinence. Links between depression and bowel control have also been reported (Buckley et al., 2007)<sup>12</sup>. The need for an integrated strategy on the management, prevention and clinical identification of incontinence has been identified. The cost of incontinence is estimated

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<sup>7</sup> Abrams, P., Cardozo, L., Fall, M., Griffiths, D., Rosier, P, Ulmsten, U., Van Kerrebroeck, P., Victor, A., & Wein, A., (2002). 'The standardisation of terminology of lower urinary tract function: Report from the Standardisation Subcommittee of the International Incontinence Society.' *Neurourology and Urodynamics*, 21, 167-178.

<sup>8</sup> Hunnskaar, S., Burgio, k., Clark, A., (2005) Epidemiology of urinary and faecal incontinence and pelvic organ prolapse. In Abrams, P., Cardozo, I, Khoury, S & Wein, A., (Eds.) *Incontinence: 3<sup>rd</sup> International Consultation on Incontinence*. International Continence Society, Bristol, Montreal.

<sup>9</sup> Perry, S., Shaw, C., Assassa, P., (2000). An epidemiological study to establish the prevalence of urinary symptoms and felt need in the community: the Leicestershire MRC Incontinence Study, *Journal of Public Health*, 22 (3), 427-434.

<sup>10</sup> Landefeld, C.S. (2007). State-of-the-Science Conference on Continence, available [www.nih.gov/news](http://www.nih.gov/news)

<sup>11</sup> Chiverton, P.A., Wells, T.J., Brink, C.A., Mayer, R., (1996). Psychological Factors Associated with Urinary Incontinence. *Clinical Nurse Specialist*, 10 (5), 229-233.

<sup>12</sup> Buckley, B., Wagg, A., & Winder, A., (2007). Emotional Well-being in Faecal & Urinary Incontinence, *Continence UK*, 1 (1) 66-69.

at around 0.85% of the total NHS cost in the United Kingdom (Continenace Foundation, 2000)<sup>13</sup>.

The Project and the evaluation is funded by the European Union through INTERREG IIIA. Cooperation and Working Together (CAWT) is a partnership arrangement whereby cross border cooperation in health and social care is supported. CASP was initiated by the CAWT Physical and Sensory Disability Steering Group and the Project Board comprises representatives from the Western Health and Social Care Trust which at its formation included Foyle Health and Social Services Trust (H & SS Trust), and Sperrin Lakeland H & SS Trust, Donegal representatives from the HSE and the United Kingdom based patient support group Incontact (Action on Incontinence). The involvement of consumer groups is a central and important aspect of the Project. A Project Manager was employed on 2<sup>nd</sup> January 2006 to provide a pivotal role in representing all stakeholders, spearheading the awareness campaign and coordinating the successful delivery of all products, such as the Resource folders developed during the Project. The management structure of the Project is by way of a Project Executive, an Operational Support and Clinical Line management, and administrative and clerical support. Quality is facilitated by a Project Assurance team.

The Project has worked in a number of ways ranging from increasing general public awareness and understanding to advocacy, improving paths to support and referral. The Project held a launch in Lifford, Co. Donegal for the Resource pack for professionals which was produced and distributed over 500 copies to General Practitioners, Health Centres and practice nurses with the further 500 copies in production. Requests for more Resource folders have been received from people who have read about it in professional publications. A workshop which brought consumer, voluntary groups and professionals together was held on November 14<sup>th</sup> 2006 in Enniskillen and four Continenace Awareness Information Sessions were held to coincide with Continenace Week in Donegal in 2006. Postal questionnaires were sent out in Spring 2006 to 836 stakeholders and questionnaires were also given to consumers at

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<sup>13</sup> Continenace Foundation, (2000). Making the Case for Investment in an Integrated Continenace Service.

continence clinics during 2006. The Project Manager visited over thirty voluntary and community groups to give talks about the Project and continence issues and has received requests for further visits.

The Project had three main aims:

1. To identify service provision (Statutory, Voluntary, NGO, Commercial Sectors) on both sides of the border and identify gaps in areas in which simple measures can lead to more effective service provision, cooperation and resource use.
2. To promote public and professional awareness on continence problems in order to facilitate the understanding and prevention of such problems, earlier help seeking by people affected by them and more effective professionals practice with regard to identifying and referring people affected.
3. To offer information and support to people with continence problems in order to promote easy access to services, support and products and facilitate community and cross-border patient-led support activities.

### **1.3` Terms of Reference**

Evaluation of projects is given significant emphasis by CAWT and it is recommended that both internal and external evaluation is carried out. The Continence Awareness and Support Project is one of many CAWT Projects and commenced on January 2<sup>nd</sup> 2006 with the appointment of the Project Manager. The project duration was twenty-four months and concluded on 31<sup>st</sup> December 2007.

Following receipt of the Terms of Reference for the project, Anna Edwards provided a proposal for the external evaluation and this proposal was accepted by the board. It was agreed that the external evaluation would include the following information in line with the Guidelines for the evaluation of INTERREG Projects, December 2007:

#### **Project Performance**

- The extent to which the project aims have been met
- Quality of the project; strengths and gaps
- Project management system
- Project board communication

#### **Project Impact and Findings**

- Overview of services available in jurisdictions concerned
- Comparison of services
- Identification of gaps in the services
- Project outcomes and products
- Any other additional information, i.e. coordination, training or educational needs
- Recommendations and lessons learned

#### **Partnership and Sustainability**

- Cross border and inter-agency aspects and communication

- Cross border agreements secured
- Development from the project to a larger scale programme
- Sustainability of the project
- Increasing access to support and training for patients and professionals

This report comprises the findings of evaluative research conducted externally on the Continence Awareness and Support Project. A report is provided regarding the analysis of the users' and professionals' questionnaires which can be found in Appendix 7.5.

## 2 METHODOLOGY

The following sources of data were used to gain information encompassing as much feedback as possible regarding the programme impact, project performance and success of the partnership as well as recommendations for sustainability and extendibility:

1. Telephone Interviews with Project Board members (Appendix 7.1)
2. Telephone Interviews with Consumers (Appendix 7.2)
3. Telephone Interviews with Professionals (Appendix 7.3)

Table 1 below shows how each group contributed to the evaluation.

**Table 1 – Methodology and Rationale**

<b>Methodology</b>	<b>Rationale</b>
Telephone Interview with all Project Board members including Project Manager, Project Executive and Project Assurance	To discuss through the use of a structured qualitative questionnaire, Board members' perceptions of the Project in terms of expectations, achievement of objectives and their recommendations.
Telephone Interviews with Consumers	To discuss the impact of the Project and gain recommendations and perspectives on the sustainability and development of the Project from consumers and voluntary groups.
Telephone Interviews with Professionals	To discuss the impact of the Project, perceived changes in awareness in professionals and consumers and gain recommendations regarding the sustainability of the work of the Project and other issues.

## 2.1 Sampling

Table 2 below summarises the sampling strategy for each group of respondents.

**Table 2 – Sampling Strategies used**

<b>Group</b>	<b>Sampling</b>
<b>Telephone Interviews with 13 Project Board Members including Project Manager</b>	100% of those who were members of the Project Board at the time of the evaluation. This meant that previous Board members who had to leave owing to work developments were not included.
<b>Telephone Interviews with Professionals</b>	25 professionals were selected using random sampling to ensure representation of all three geographical areas by the external evaluator. Names were selected from the database of those who had attended the workshop and those who returned postal questionnaires.
<b>Telephone Interviews with Consumers and Voluntary Groups</b>	15 consumers were selected using random sampling to ensure representation of all three geographical areas by the external evaluator. Names were selected from the database of those who had attended the workshop and those who returned postal questionnaires. Owing to the difficulty of contacting consumers, purposive sampling was also used facilitated by the Project Manager.

## **2.2 Ethics**

Ethical considerations are essential and the British Psychological Society ethical principles (2000) were adhered to. Workshop participants and questionnaire respondents had already been asked for their permission to be contacted by the Project and this was deemed sufficient in terms of consent. On contacting respondents, the evaluator assured participants of anonymity in that no names were mentioned in the report. Participants were also asked whether what the evaluator had written was an accurate representation of their viewpoint. Finally, dissemination of the findings is essential and participants were informed that the report will be made available on the CAWT website.

Telephone interviews were scheduled by the evaluator who asked respondents for a convenient day of the week and approximate time of day.

Both quantitative and qualitative information was incorporated in the evaluation. A small amount of quantitative data were generated by attitude rating scales and qualitative data exploring respondents' perspectives and experiences were obtained through the use of open questions and probing. The research design employed one methodology; telephone interviews, to ensure optimum response rate and convenience for respondents.

### 2.3 Telephone Interviews with Project Board, Consumers and Professionals

Telephone interviews are an effective method for gaining an in-depth perspective from one participant and have equal accuracy rates as face-to-face interviews (Carter & Henderson, 2005)<sup>14</sup>. Advantages include the ability to create rapport and trust with respondents especially where sensitivity and personal experience are involved.

Other advantages include convenience and cost-effectiveness when the sample population is geographically scattered. Disadvantages include being limited to people who have telephones and offering a diminished degree of anonymity, a fact which could result in a biased response (Parahoo, 2006)<sup>15</sup>. Respondents were assured of anonymity in that no names would be mentioned in the report of the evaluation also that names were not written on the recording schedules used by the evaluator. A participant number was written on the question schedule. The numbers were assigned by the evaluators and only the evaluators knew them, thereby ensuring anonymity. Consumers and professionals had been asked, when they completed the questionnaires whether they would give contact details in the event of further research being undertaken by the Project and a database had been compiled from this extensive information.

Respondents were asked by the evaluator whether they would mind being quoted on particularly pertinent excerpts which were read back to them.

Structured interviews for participants were devised by the evaluator and stakeholders from the CASP project board and piloted with two participants for each of the three questionnaire schedules. Following the pilot, some changes were made to the Project Board members' questionnaire. For example: question 2 '*Please explain: (the expectations elicited in question 1)*' was omitted because of repetition.

Question 5 was changed from '*What would like to do differently?*' to '*What would like to have done differently?*'

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<sup>14</sup> Carter, S., & Henderson, L., (2005) in Bowling, A., & Ebrahim, S., (Eds.) Handbook of Health Research Methods. Maidenhead: Open University.

<sup>15</sup> Parahoo, K., (2006). Nursing Research: Principles, Process and Issues. London: Palgrave Macmillan.

The rating scale at question 7 was changed from '4= *completely*, 3= *mostly*, 2= *partly*, 1= *not at all*' was changed to,

<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
<i>Very successfully achieved</i>			<i>Not successfully achieved</i>

The Project Board interview took 20-45 minutes to complete and comprised 21 questions organised into four sections; project objectives, management structure and processes, developing services and partnership and collaboration aspects.

The questionnaire for consumers comprised six questions and took 10-20 minutes to complete. Client group and location within the three health board areas were recorded prior to contacting the respondent and details were taken of what contact the respondent had had with the Project; i.e. attended workshop, completed postal questionnaire.

The questionnaire for professionals comprised twelve questions and could be completed in 10-20 minutes. Following a pilot with two respondents, the following changes were made:

The rating scale at question 3 was changed from  
'Yes Mostly A little No' to  
'Mostly A little Not at all'

A question was also added '*How might continence services be affected by the re-structuring in the health service?*'

## 2.4 Recommendations for Future Evaluation of Projects

For future evaluation, the following points are recommended:

- The development of questions requires time and focus. Owing to the late start of the evaluation, the development of the questionnaires with the Project Board was rather hurried and resulted in additional time being spent by the evaluator working with Quality Assurance of the Project revising the consumers' questionnaire.
- The importance of piloting questions was highlighted by the current evaluation.
- Including both consumers and professionals was valuable in gaining different perspectives on the impact and sustainability of the programme.
- The involvement of more consumers could be discussed; this may entail personal contact from the Project to enlist the consent of participants.
- The results of the evaluation indicate that it is too early to assess the impact of the Resource folders and it is recommended that discussion takes place regarding follow-up of the folders with the possibility of further evaluation in another six months.
- The timing of the evaluation was problematic in that people were contacted over a year after attending the workshop or receiving a questionnaire. Building in evaluation times at the start of the Project could help to optimise the timing more effectively.
- Baseline measures of indicators such as numbers of referrals are in line with best practice in evaluation and can enable an assessment of whether the intervention or project has made a difference.

### 3 RESULTS

The table below indicates the number of each group who participated in the evaluation:

**Table 3 – Numbers Consulted for Evaluation**

<b>Group</b>	<b>Number</b>
Telephone Interviews with Project Board	11
Telephone Interviews with Consumers	11 ( <i>target of 15</i> )
Telephone Interviews with Professionals	25

#### 3.1 Telephone Interviews with Project Board members

##### A Project Objectives

##### 1. What did you expect the Project to deliver on when you set out?

Expectations included broad quantitative outcomes such as deliverables and broad knowledge and attitude based outcomes. Overall people expected that the Project would result in improved and more accessible services for patients. The expectation expressed by the majority was that the Project would increase awareness in the public and professionals that continence can be managed and of the routes to referral. Mapping of services, gaps and barriers to referral was also expected to be an outcome. Addressing equity and standardization of services on both sides of the border was another expectation which highlighted the importance of working collaboratively across statutory, voluntary and consumer organisations. People qualified this hope by saying that equity of service is rarely achieved in any aspects of health care.

There were a couple of core hopes which some felt were not realised. First of all, a greater consumer focus had been expected although it had become clear once funding was secured that there was more emphasis on service providers. This emphasis was

corroborated during the evaluation when it became apparent that it was easier to contact professionals than consumers. This, however, requires recognition of the stigma of incontinence which is a major factor in encouraging service users to come forward. A further hope which was not borne out was the creation of a post or other resources. However, this was not defined as an objective of the project. More emphasis was also hoped for on services for people with disabilities, particularly physical and sensory disorders such as cerebral palsy and multiple sclerosis.

## **2. What do you consider are the positives or successes of the project?**

Progress in raising awareness in the general public was seen by most Board members as a success. Instrumental to developing awareness were the workshop, the Project Manager's visits and the Resource folder. It was emphasised that raising awareness is a process rather than a finite point and that the work which has been initiated during the Project will continue as evidenced by the demand for more visits and Resource folders. Respondents pointed out that the effectiveness of the Resource folders cannot be assessed yet, therefore the evaluation is almost occurring too early.

Tangible successes from the Project included:

- The Resource folder
- The workshop for bringing professionals and a small number of consumers such as parents together
- Cross border joint training, for example for physiotherapists and Continence Advisors.
- Awareness has spread to educational contexts as a result of the workshop and which involved the Health Promotion unit of the HSE in Donegal. In December 2007 69 Special Needs Assistants received training in continence issues and a further 80 have requested training.
- The forthcoming inclusion of a section on continence issues in the forthcoming Student School Diary in Donegal, also initiated by Health Promotion. This is particularly important as it involves the post-primary sector and can therefore

help to tackle the stigma associated with continence. This initiative will also be widened to be included nationally in secondary school students' diaries.

- Links and networks have been forged between the professionals involved on the Project Board. As a respondent commented; "The biggest success has been the links between professionals of different disciplines and geographical areas. It's given good structure for links to be made formally and informally. The workshop was very important; it got consumers and professionals together and talking and identifying barriers."
- Focus group planned between Northern Ireland and Irish Continence Group in January 2008.
- The achievement of a helicopter view of service provision through cross border collaboration.

The failure of the health service to bring continence services to the fore was highlighted:

"Continence is a hidden problem and the project has helped to bring this issue to the fore. Some people weren't aware there are Continence Advisors and it's the fault of the statutory bodies who need to publicise this service."

### **3. What changes in behaviours or practice or changes in attitude are happening as a consequence of the Project?**

The majority of respondents perceived that changes were occurring and foundations had been established to continue these developments and included:

- Business case planning
- Cross border collaboration in training
- Including support organisations such as Incontact
- Service planning for children with intellectual disabilities
- Joint applications for training funding
- Some greater readiness to come forward and be referred among consumers.

Around a quarter of the group felt that there were no apparent changes. Factors influencing this were that some services were already operating at an effective level and that other service related developments were influencing change rather than the

Project such as the introduction of an IT system for managing the Continence services, the appointment of a Urology Nurse Specialist under ICATS, also a delivery service for aids and appliances.

#### **4. What are the weaknesses of the Project?**

Some felt they may have benefited from more guidance and clarity from the CAWT development centre about the Project management process. In particular, project members felt unsure about the project boundaries and autonomy of the project board itself in relation to decision-making. Adding to the lack of focus were the different perspectives of the different Board members and the re-structuring of health services on both sides of the border, which was happening simultaneously as the Project. It may be argued that any one of these factors would present difficulties associated with any new project board in finding its focus.

Some felt that there was significant bureaucracy associated with the PRINCE2 project management system (and documentation requirements) at the start of the Project. This was perceived by some of the project board to have resulted in utilising considerable resources and time that may have been better employed in planning and implementation of the project itself. It is recognised, however, that for staff and Project Board members who had not previously used PRINCE2, there may be a learning curve. Feedback from the Project Board for the CAWT development centre was that their contribution at the start could have been more constructive in supporting Board members and in establishing workable communication systems. The Project Manager and the Project Board have provided detailed feedback to the CAWT development centre. The CAWT development centre have accepted the feedback and welcomed the opportunity for learning. Representatives from the CAWT development centre have reported that it is not uncommon for projects to suffer from some degree of ambiguity at the start and to develop clarity as they progress.

With regard to the focus of the Project, there was a perception that consumers who could benefit from support had perhaps not been reached:

“Getting in touch with people who aren’t accessing services and we had no way to access their views. Maybe we’ll have to get to them through other services such as Women’s health.”

## **5. What would you like to have done differently?**

Responses can be differentiated into actions which could have been taken prior to or at the start of the Project, during the project and follow-up actions. Actions which it was felt could have been taken in order to establish the Project included:

- Assemble the Board earlier to enable more effective focus and less drifting although it could be pointed out that this is inevitable in the life of any group.
- More planning and clear focus before the Project Manager was employed could have helped.
- Involve a business facilitator to enable meetings to have been more productive and focused from the start.
- Half day training or so on project management systems was provided but rather too early in the process
- More health care professionals who ‘work at the coal face’ could have been part of the Project Board rather than senior managers. The changes in the membership of the Board were also perceived as a slight hindrance to the work.

Action which respondents felt could have been carried out during the Project included:

- Focus on targeting GPs earlier.
- More actions of direct benefit to clients
- Building awareness through general health programmes such as cervical screening programmes or women’s health or prostate clinics to access those who aren’t making use of services.
- Securing more involvement and commitment from voluntary organisations and statutory services.

Actions for the future included:

- Concern about ensuring that the Resource folders are not just left on shelves unused.
- Evaluate again in six months' time to assess the impact of the folders and any other initiatives.

**6. Do you feel that there have been any changes in awareness or in the willingness of people to ask for help with continence problems since the start of the Project?**

While a few respondents felt unqualified to judge this, most Board members commented that awareness among professionals has certainly been developed by the CASP. A quarter of the Board said that awareness among the public has been increased as demonstrated by the Health Promotion Unit in Donegal's work within schools, discussion at the workshop and referrals from groups whom the Project Manager had visited. It was cautioned again that the impact of the Resource packs couldn't yet be assessed.

A few respondents reported they had seen no change and where continence services had been good already, they felt the Project made little impact. A further point was that any increase in awareness might have been the result of a number of factors such as general service review initiatives and awareness raising across the health service.

**7. Thinking of the Project objectives, could we consider each on and rate the extent to which you feel it has been successfully achieved then look at what you feel are the successes, barriers, and ways forward.**

**Table 4: Rating of Achievement of Project Objectives**

<b>Very Successful</b>				<b>Not Successful</b>
<b>4</b>	<b>3</b>	<b>2</b>		<b>1</b>

<b>Objective</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>Not rated</b>
The project has succeeded in identifying service provision on both sides of the border	6	5			
Gaps in provision have been identified	6	2	2		1
The project has increased public awareness		5	3	1	2
Awareness among professionals has been increased through the project	4	4	2		1
Progress has been made in making professional practice more effective.	2	4	4	1	
Information and support has been made more accessible	5	4	2		
a) to professionals					
b) to consumers	2	3	4	1	1
Community support activities have been facilitated	2	7	1	1	
Cross border support activities have been facilitated	3	5		2	1

The results shown in Table 2 suggest that the objectives most successfully achieved during the Project were identifying service provision, gaps in provision and making information and support more accessible to professionals. To some extent ‘increasing awareness among professionals’ and ‘making information and support more accessible to professionals’ are repetitive. The facilitation of community support activities was seen as having been quite successfully achieved primarily by the Project Manager’s visits. Least successfully achieved objectives were making information and support available to consumers and increasing public awareness in general. This could be attributed in part to the difficulties experienced in getting consumers/service users to participate.

Perceptions regarding the achievement of each objective will now be discussed along with barriers to achievement and possible solutions or ways forward.

- i) **The project has succeeded in identifying service provision on both sides of the border**

As one of the most successfully achieved objectives, it was pointed out that the questionnaire analysis was instrumental in this. Difficulties included methodological problems with the questionnaires which, it was suggested could have been improved by being less rushed and having a more extensive pilot stage to allow input from the Project Board to help ensure that optimum levels of information were elicited from respondents. One item which could have been included was to ask about waiting times for referral and how many patients are seen in clinics.

**ii) Gaps in provision have been identified**

Another objective which people felt had been successfully achieved through the questionnaires and workshop and which highlighted the lack of equity between services. Asking questions of service providers was seen as a useful exercise yet the achievement of this objective was qualified by the idea that more questions could have been included in the questionnaire to probe the gaps. It was suggested that further information could be gained by the greater involvement of consumers and carers. Targeting the distribution of the Resource folders was seen as a way to address some of the gaps in provision.

**iii) The project has increased public awareness and information and support has been made more accessible to consumers**

Almost half of the Board said that they felt public awareness had been increased successfully through the workshop, Resource pack and launch and the visits. For others, their service was already well known in the area. Barriers to increasing awareness were the stigma of incontinence which was perceived in relation to the reluctance of the press and media to give adequate coverage to anything relating to this sensitive 'Cinderella' issue. As someone commented; "There are no pop stars promoting continence!" Difficulties in reaching the people who are in most need and have least awareness already were highlighted. A further barrier was felt to the

somewhat disappointing involvement of the voluntary groups in the workshop. Possible solutions included more use of local and national radio and press, greater involvement and commitment from managers and distributing leaflets and publicity in libraries, health centres and community/voluntary centres and as part of more general health promotion such as women's health and men's health screening. It was suggested that private sector advertising through the media has focused only on pads. Health Services should advertise with health promotional material to promote awareness of issues such as healthy eating and fitness.

**iv) Awareness among professionals has been increased through the project and information and support has been made more accessible to professionals**

These were seen as having been successfully achieved although it was perceived very much as work in progress. Barriers listed included the low priority and stigma as well as high workload which could result in the folders not being used and being left to gather dust. Some suggested that few people outside the remit of the Project knew it was going on. GPs were a concern to respondents having been identified as the gatekeepers to referral, it was felt that there was a danger they could just hand the folder over to the Practice Nurse to deal with (who may already be aware of referral routes). Where waiting times are long, they could be reluctant to refer patients at all. In addition, owing to the fact that effective intervention can be preventive, there is a tendency to wait until there is an actual problem. Possible solutions to these problems were to "keep hacking away" and develop ongoing training for a wide range of professionals such as GPs and other Allied Healthcare Professionals. Having measurable SMART (Specific, measurable, achievable, realistic and time-oriented) goals could also help to develop awareness it was suggested.

**v) Progress has been made in making professional practice more effective.**

This objective had been quite successfully achieved according to over half of respondents feeling that the foundations have been established, for example with joint cross border training and forums. Several said that it was too early to assess or that

they were unsure if the right people had been reached. Barriers included the prevailing attitude of GPs that;

“They tend to throw pads, pants and medication at the problem. Contenance can be cured or at least managed. If this attitude among professionals can't be moved on, it will be wasted effort.”

Lack of availability of appliances and aids and new innovations in Ireland was also seen as a major problem and could limit the work of the support agencies such as Incontact who may be more familiar with the range of appliances and aids available in Britain.

Lack of staffing was seen as a major problem in some services. Solutions offered included follow-up after the Resource packs especially with GPs, wider distribution of the packs, for example to nursing homes and ongoing training and health promotion.

#### **vi) Community support activities have been facilitated**

The majority of Board members believed this objective has been successfully or very successfully achieved through the workshop and visits. There is a clear demand for more visits demonstrating that this work will continue. Barriers considered were stigma of incontinence and its low priority on the agenda, lack of funding to free people up to network in the community and lack of training and confidence to carry out this work. Solutions offered were the continuation of Contenance Manager posts and in common with increasing public awareness to maintain the visits to groups, talking to people in the community and distributing leaflets and information in health centres and free local papers. Specific targeting actions which were suggested included:

- Develop further the work with health promotion, so far this is only in Donegal, where awareness in schools is being targeted. In transition year for secondary schools, it was suggested that continence issues could be discussed as part of a more general health promotion package.
- Setting up of support groups, for example for parents of children with continence problems

**vii) Cross border support activities have been facilitated**

Although most people thought this objective had been quite successfully achieved through the workshop, the Project Manager's and Project Board's formal and informal networking, organisation of joint training and the planned joint continence focus groups, there was a recognition that these links require further development. People felt that links made during the Project would be continued.

Barriers concerned the difficulties in ensuring standardisation of care across different jurisdictions and lack of resources as well as the low priority of continence issues in general in health care. Cross border working was also felt not to be high on the agenda for health boards and trusts. Solutions included the need to fund a post, building in regular meetings between professionals and more involvement of consumers and voluntary groups. The workshop was felt to have been the only forum which had involved service users. More commitment from management in the border areas was felt to be paramount with the need for cross border discussion of strategic issues and the consequences of organisational change and priorities. A practical solution for sharing resources suggested was the use of the continence resource centre, Enniskillen which could be used by groups to gain information. Several people felt that it was up to every individual involved with the CASP to keep the momentum going.

**B Management Structure and Processes**

**8 Do you have any comments about the effectiveness of the Project Board?**

Board members acknowledged that the Board had worked most effectively during the last six months of the project which, as one Board member pointed out, can be a natural part of group development as the group moves through the norming, storming and into the performing stages. Bearing this in mind, perhaps the Board could now consider

how best to adjourn the life of the group and its work. Barriers to effectiveness were found in the initial stages and included:

- Lack of clarity on project communication
- Numerous meetings at the initiation stages of the project
- Turnover of Board members
- Demands on Board members time (Board membership in addition to the day job)
- Lack of clarity on line management for the Project Manager
- The need for a facilitator to help facilitate meetings (planning, defining scope etc) in the early stages
- Training on dynamics of group working (cross border group working) for Project Board and project Manager
- Need to establish the Project Executive and Assurance Team at the outset
- Project board members should have been trained on PRINCE2 when they were ready to commence using it rather than prior to this.
- Given the scale of the project perhaps a reduced application of the PRINCE2 methodology would have been more efficient.
- In the early stages of the Project, liaison between the Project Manager, the Project Board and the CAWT development centre was not as effective as it could have been. The Project Manager and the Project Board have provided detailed feedback to the CAWT development centre. The CAWT development centre have accepted the feedback and welcomed the opportunity for learning.

**9. In your opinion, has the Project as a whole been worth the money?**

**10. Has the Project been a good investment for your organisation?**

- Everyone acknowledged the important contributions made by the workshop, visits, Resource packs, networking and training initiatives.
- A couple of respondents felt that the real value cannot be ascertained as yet and will depend on the use of the packs.
- There was concern expressed that the work could be forgotten about and only the larger projects are receiving continued funding.

- Some emphasised that more impact could have been achieved, for example in terms of raising awareness and breaking the taboo around incontinence.

The majority of the Board felt that the Project and the time they had spent on it was a good investment for their organisation. Gains mentioned included:

- Greater awareness among professionals, voluntary and community groups and allied professionals
- Links built between professionals
- Comparison of services which enabled some to feel assured their service was doing a good job.
- Skills in project management, cross border working and information sharing
- Over one third did not feel their time had been worth the investment because services in their area had not improved as a result.

## **C      Developing Services**

### **11.    How would you like the impact of the Project to be sustained?**

Responses related to the levels of service planning, resources, health promotion and awareness raising and follow-up from the work of the Project. Service proposals had been submitted to CAWT at the time of the evaluation and there was acknowledgement that the Resource packs would need follow-up. Suggestions included:

- The need for organisational support for continence services was required from management.
- Building on the links which had been forged during the Project with regard to professional forums, joint training and multi-disciplinary working, such as with health promotion and providing training for nursing home and other staff was felt to be vital in extending the work.
- Targeting of GPs in terms of awareness and training where appropriate
- Delivering preventative group exercise classes to post natal women on a cross border basis

- The creation of a specialist Paediatric Continence Advisor post
- Joint cross border media initiatives such as holding a North West Continence Week both sides of the border with the support of the local press was an idea put forward to help to develop public awareness.

**12. Do you have any suggestions for developments that should be taking place?**

This question was designed to elicit ideas about what has not happened but that could be occurring to consolidate the work of the Project. Suggestions can be grouped into resources, preventive and health promotion and continuing professional development. The hope that the Project can develop a business plan and training agenda was voiced with the idea that there could be joint mainstreaming of initiatives, co-funded by the different authorities.

In terms of resources required, Board members highlighted:

- The need for more posts, in particular a Paediatric Continence Advisor and continence trained physiotherapists in paediatrics, intellectual disabilities and physical and sensory disabilities.
- Continence clinics for children and the targeting of post-natal women through group exercise sessions were raised as possible developments.

Health promotional work which was suggested included

- “a rolling health promotion campaign and a two year media blitz.”
- Extending collaborative work into the education sector with teachers and parents was mentioned. In order to resource this, an extra post or part of a post would be required, it was argued.

Continuing professional development included:

- Extending the training agenda to allied health professionals and staff in nursing homes as well as increased focus in intellectual disability settings. Respondents felt that major gaps were in the disability and paediatric fields as well as the lack of support from GPs.
- Dissemination of best practice among professionals was also felt to be an issue which the Project had not addressed sufficiently.

## **D Partnership Aspects**

### **13. Any thoughts about the collaborative nature of the project in terms of involving organisations from statutory, voluntary, community, industrial sectors/multidisciplinary agencies?**

Positives about the collaboration engendered during the Project were:

- The involvement of Incontact
- Recognition of the multi-disciplinary nature of continence management
- Consultation with voluntary groups to produce the Resource folders
- Awareness raising, for example from health promotion in Donegal
- The good communication between Board members who work 'on the coal face'.

For some, the Project enabled them to feel less isolated in their work and the workshop was seen as very important in its inclusiveness. Where collaboration could be strengthened was working with a greater range of voluntary agencies such as Brainwave and the inclusion of more support groups and professionals working with people with sensory and physical disabilities. The importance of working in general settings in health promotion e.g. parent-toddler groups was highlighted along with the perennial problem of low priority and stigma. The need for a second workshop was suggested to plan action for the future.

### **14. How might the cross border links built during the Project be supported and developed?**

The following were suggested:

- Regular meetings, an annual forum, joint training and speakers,
- Continuation of the networking and links developed during the Project.
- Joint preparation of business cases was suggested. Further funding would be required for some of these initiatives.

- In terms of support from management and the statutory organisations concerned, Board members highlighted the need for better collaborative managerial work.
- It was also felt that it was up to each individual to continue the work which CASP had started.

**15. How might services be affected by the current re-structuring of health services on both sides of the border?**

Themes here were dominated by lack of certainty. Hopes were expressed that the formation of a “supertrust” in Northern Ireland and the extension of HSE West to Limerick would result in greater equity, harmonisation of services and sharing of information. In NI, the creation of ICATS (Integrated Care and Treatment Centres) and Primary Care teams was felt to be potentially positive. Another respondent was confident that new posts would be created. Possible negative impact included the centralization of resources and facilities in the larger urban areas and the possibility that the issue of continence could be lost in teams with a wider focus where all services are vying for resources.

**16. How could support agencies such as Incontact and the Continence Foundation be involved at local level and adapted to local needs?**

Suggestions here included the need for:

- Adaptation to terminology used in Ireland and Northern Ireland
- Development of local branches
- Information lines for consumers and professionals
- Inclusion of the evaluation report on the Incontact website
- Presentations for community and voluntary groups

### 3.2 Telephone Interviews with Consumers

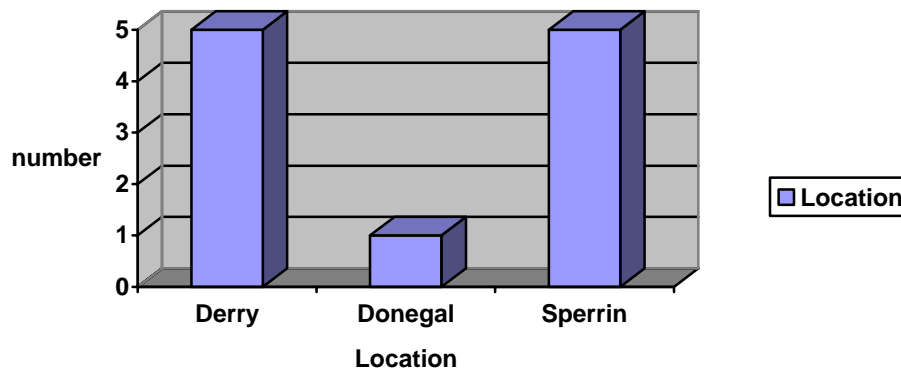
A total of 11 consumers were interviewed although, in keeping with the observation made by Bowling (2005)<sup>16</sup> a number of call backs were necessary to establish a suitable time for the interview. Failure to reach the target of 15 interviews with consumers highlights the particular difficulties of accessing this group. Telephone interviews may not have been the most appropriate instrument to tap views about a stigmatising condition but were selected owing to the tight timescale. The Project database compiled from the professionals' and users' questionnaires and workshops was used and almost one third of those contacted had only completed the postal questionnaire. One problem was that people's contact details had changed or they had left the voluntary organisation. Another difficulty was that a number of contacts reported that continence issues were of no relevance to their clients. Some indication of this from the postal questionnaire and database would have been helpful. Note that for a few questions, more than one answer could be applicable therefore replies may total more than 11. The small number of interviews conducted with consumers means that these results should be interpreted with caution.

The chart below indicates the location of the respondents and shows that while Derry and Lakeland and Sperrin areas were well represented, only one individual in Donegal was contacted.

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<sup>16</sup> Bowling, A., & Ebrahim, S., (2005). Handbook of Health Research Methods. Maidenhead, Open University Press.

**Chart 1: Location of Users Interviewed**



The table below shows that the majority of consumers represented either older people or support and voluntary groups. No users representing young people and children were contacted and this could be due to a number of factors such as lack of involvement of these groups, lack of awareness or lack of contact with the Project. The postal questionnaire achieved a more representative sample with 67% users being under 65.

**Table 5: Client group Represented by Consumers**

Voluntary : MS, Stroke, Alzheimer's Society, Mental health, physical & sensory disability, women with disabilities, Parkinson's	7
Children & young people to 18 years	0
Older people 65+	7
Under 65's	3

Table 6 below shows that almost half of the users surveyed had received visits from the Project Manager, almost a quarter had attended the launch of the Resource pack, two had attended the workshop while four had completed the postal questionnaire. The inclusion of those who had limited contact with the Project is positive with regard to methodology as it reflects a random sampling strategy and therefore should be more representative of a wide range of perspectives.

**Table 6 Type of Contact with the Continence Awareness Support Project**

Attended workshop	2
Postal questionnaire	4
Visit from Coordinator Mary Murphy	5
Attended launch of Resource pack	3
Other – invited to launch, unable to attend, ongoing contact with CASP	2

**2. What difference has your contact with the Project made/ what impact has this had?**

Responses indicated the positive impact of the Project. Over half of people surveyed reported that their contact with the Project had helped to increase general awareness of types of continence problem, break the silence and make people aware that help is available. Where people had received visits, they acknowledged the value of this work and that the discussion had been informal and relaxed which enabled people to broach the subject more easily. They commented that leaflets had been taken and that the Resource folders were useful as a resource. One person had used the referral telephone numbers but others were unable to comment on whether the members of their organisation had taken the matter any further.

One respondent felt they would have liked to be shown some of the practical items and appliances at the talk in addition to the leaflets. There was a feeling that knowledge of the Project as well as of continence services is patchy and also that the impact of the Resource packs cannot yet be assessed accurately. People felt that a good start had been made which requires further development. Where people commented that the Project made no difference to their organisation, their contact had been limited to the postal questionnaire.

Comments included:

- I work in the border areas and Donegal can fall short e.g. of the service of a neurologist. I thought it was excellent to have the project and launch of the pack and would love to see it continue. For years we had no access to specialist

nursing for MS in the NW but we were lucky and it makes a tremendous difference to people's lives.

- It gave information for families and patients. It was useful and gave us a push in the right direction. It's such a personal thing and it was good to get people talking about continence.
- It made people aware. They were guarded owing to the sensitive issue but they took the leaflets and information and were grateful. I don't know whether people followed on and went for referral afterwards. I wouldn't have known about the service if we hadn't had the visit.

### **3. What changes would you like to see happening as a result of the Project?**

Replies to this question focused unanimously on the need to continue to provide information and awareness raising events as well as increasing access to services. In particular those with disabilities were mentioned as needing better access to services. More generally, people felt that continence issues could be more discussed along with general health as part of primary health care. The idea was expressed that with any form of stigma, it is important to keep on bringing discussion into the open. As one person commented:

“The Project has done fantastic work yet there are groups who haven't been reached. A lot of people suffer and this help is invaluable.”

Some had suggestions for publicity, for example, information and leaflets could be left in GP surgeries, chemists, pharmacies, libraries, newspapers and publications for groups such as older people. A couple of respondents requested that the visits to community and support groups be continued. For a minority who were already benefiting from good services, they were unsure what improvements were needed.

**3. Do you believe that service users should be more involved in the planning of further projects in continence awareness?**

This question was really asking whether service users had been sufficiently involved in the Project. Most people felt that including consumers is vital for gaining their views and in developing effective ways of reaching those who require help. The role of the workshop was commented as important in bringing consumers and professionals together although there was a concern that consumers were a minority there and the Project had not gone far enough in including users:

“It would be good if people would come out from behind the door. People deny having a problem so there’s not much you can do. If only the people affected would come out and talk. The workshop people weren’t sufferers themselves I don’t think therefore the information won’t necessarily get to those who need it. I was surprised (from workshop) that continence problems are so widespread.”<sup>17</sup>

The barriers to involving users were mentioned and it was suggested that carers and carers’ groups, disability groups could be targeted for visits and information giving. There is evidence that some carers would have liked to attend the workshop but were unable to attend as they didn’t have anyone to cover their caring role

**4. Do you have a Resource pack?**

The majority of those interviewed had received a Resource pack as shown below which is evidence for successful distribution. All those who had not received a pack said they would like to be sent a copy.

**Table 7: Resource Pack Distribution**

Yes	No
6	5

**5. Is there anything you feel is missed out of the pack?**

The following comments were offered:

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<sup>17</sup> Organisers have reported that some of the attendees were ‘users’ of the service and attended the workshop under the disguise of being either a member of a voluntary group or within a professional role.

- Aids and the availability of aids; people don't know where things are available from and whether they have to pay or not. A list of resources and appliances and what's available free or at a subsidised cost or not would be good.
- The packs are well put together. The only question is does it come in different formats? It's in quite large print but what about things like an audio version?

## **6. Any other comments?**

Concluding comments reflected the important work which had been achieved in terms of raising awareness. People felt strongly that the work should continue as the following comments reflect:

“Don't let the thing die, it will be a long slow process, keep hammering away!”

“I'd hope the work of the project would continue. It was a great initiative but it's only a start. We need to start sharing services (cross border) now.”

As one person mentioned, once awareness is raised this can increase consumers' expectations that there needs to be service provided and therefore pressure can be mounted on health service providers.

The difficulties and importance of opening discussion and maintaining the momentum was emphasised:

“A general principle is, regarding sensitive issues such as continence and abuse; the more we talk the more we free up the topic. Get it in the open and involve as many services as you can. Have no sacred cows!”

“It's a very positive venture. If people have somewhere to go and talk and get information and help, it's good. Information is power and getting the information out there is the key!”

There were a number of favourable comments about the visits to voluntary groups and it was felt that these visits should be continued and extended to Day Centres and Senior Citizens' Clubs. Being approachable, informal and creating a relaxed environment was found to be effective in enabling people to talk.

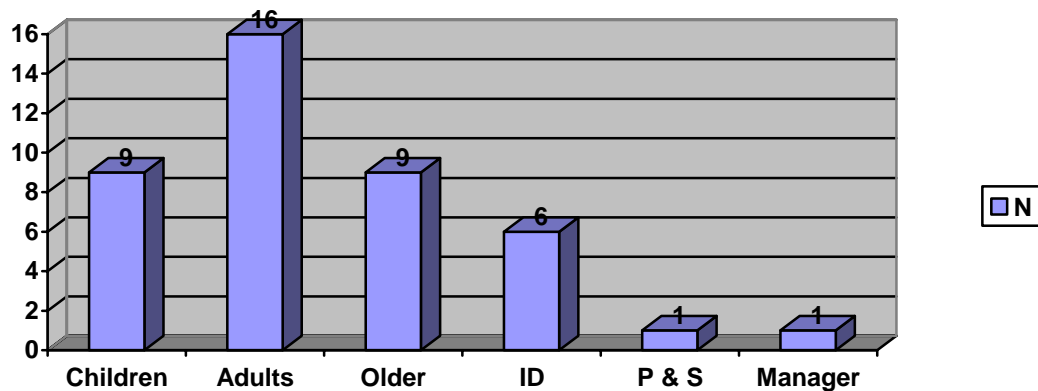
In addition to the positive feedback for the Project, there was some frustration with regard to actually improving services and some voiced that more support is needed from statutory organisations. More user involvement was said to be important. A further issue identified was the need for training for physiotherapists in working with clients with disabilities including physical and sensory or learning disabilities, as someone suggested:

“Professionals like physios need more specific training in working with people with physical and sensory disabilities. For example to help people know if they’re doing exercises correctly. It’s hard if you lack sensation in the lower part of the body. Training for the individuals themselves with physical disabilities would be good so you know if you’re doing exercises right. It’s important in learning disability too, for example where people may not have the ability to explain to a professional.”

### 3.3 Telephone Interviews with Professionals

Chart 2 below shows the client groups with whom professionals interviewed work. It can be seen that almost two thirds work with adults while over a third work with primary and post-primary school children or schools and over a third work with older people. Almost a quarter of the sample work with people with an intellectual disability while one person worked with physical and sensory disabilities and one was a manager. Occupations included continence nurses, continence link nurses, physiotherapists, care assistants and a consultant gynaecologist. Settings of work included residential, hospital and community.

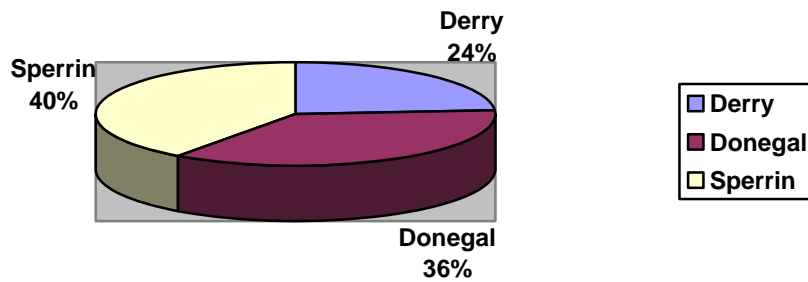
**Chart 2: Client Group**



Chart

3 below indicates the location of work of the sample of professionals interviewed. It will be observed that those working in the Derry area are slightly under-represented.

**Chart 3: Location of Professional Interviewed**



**1. What contact have you had with the Continence Awareness Support Project?**

**Chart 4: Chart to Show Type of Contact with Project**

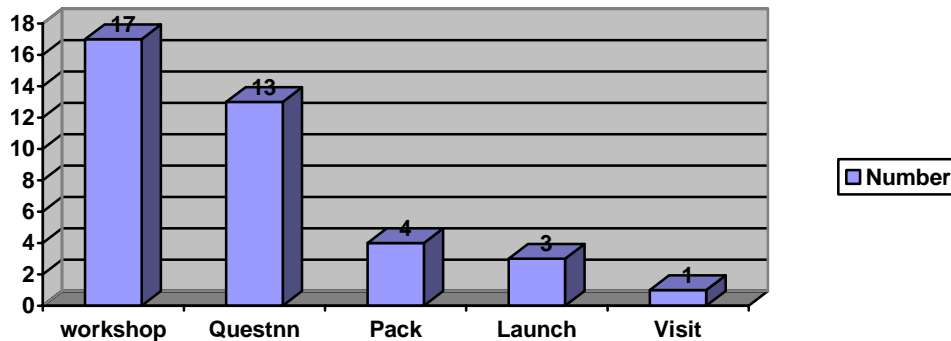


Chart 4 above shows that over two thirds of those interviewed had attended the workshop in November 2006, over half had returned postal questionnaires, 16% had received the Resource packs, 12% had attended the launch of the packs and 1 person's organisation had received a visit from the Project Manager. The time which has elapsed since the workshop and questionnaires could well be a limitation on respondents' views of the Project. For a significant number, completing the questionnaire was the only contact they had prior to the evaluation. This could skew the results towards being rather patchy and negative.

## 2. What were your expectations of the Continence Awareness Support Project?

**Table 8 : Professionals' Expectations of the CASP**

Theme	Number
Update and increase awareness for professionals	8
Improved services in border areas	6
Coordinated cross border approach	4
Increase awareness in general and tackle taboo	4
Compare services	1
Gain a post	2
Expected talk and no action	3
Learn about CAWT	1
Unsure	3

Table 8 above shows that the most prevalent expectations were that the Project would update and increase awareness for professionals followed by improved services possibly with a cross border dimension. Some respondents mentioned increased awareness for consumers with regard to treatments and referral routes. A few people said that they had completed questionnaires and had heard no more from the project until the evaluation phone call and others were cynical as to the effectiveness of projects in general. A few of the comments were:

- I thought it would be about talking and nothing being followed up. It was good to have the real life session and people's stories and it's good to know there's support and help there.
- Guidance for staff; we're a residential home so our staff aren't necessarily qualified nurses but care assistants.
- I expected to gain awareness of the difficulties associated with and extent of the problem, its impact on people's lives. I'd thought it was for the people involved in treatment and found it incredibly useful.
- Expectations weren't high because we've been down this road often. Our problem is that we have no funded staff to work in continence.

### **3. Were your expectations met?**

Those who attended the workshop found that hearing different perspectives had been useful. A few realised that their services were more adequate than in other areas and some commented on the information they had gained. Criticisms of the workshop were that it did not progress to any practical action planning and another respondent had a concern that sufficient relevant stakeholders were represented. Those who had received the Resource pack, training or literature from the Project appreciated these. One quarter were not impressed because they had not heard anything since completing the questionnaire. For a minority, the workshop did not present them with new learning as they were already established as an effective service. Comments included:

- Got more information than I'd expected and learned a lot, I liked hearing the statistics and different medications available.
- It was good to hear different people and perspectives, especially parents but they didn't go into a lot of practical detail.
- I learned the services here are better; it's easier to access information. Over the border in Donegal the Public Health Nurses are like our District Nurses as well as health visitors; it's a wider remit.
- Although there was a lot of talk, it wasn't about practicalities (at the workshop). I'm very involved in continence issues and I'm unsure whether the right stakeholders were there and I've had no contact with the project before or since the workshop. It felt like a civil service project that went nowhere.

#### **4. What impact do you think the Project has had on raising awareness of continence services?**

Only just over a quarter of professional respondents felt that the Project had had a direct impact on awareness. Comments, however, highlighted the difficulties inherent in publicising the issue of continence and the fact that attitudes are also affected by general trends in society. There was a perception that the stigma of incontinence still is strong for younger people. This may sound negative yet responses showed that real actions had been initiated by contact with the Project. These included health promotion in schools, training of Special Needs Assistants in Donegal, discussion among professionals and referral of patients. Those working in residential settings said that they can feel isolated therefore the Project had great potential and helped by giving them updates. Comments indicated a concern that there is much more work to do and that any inroads made so far are only a start as the following comments demonstrate:

- There's more awareness out there and health professionals talk about it more but it's just the tip of the iceberg. People are more open for example they'll pick up leaflets at stands now whereas before it was like mental health issues; people took the leaflets but when you went away.
- I've referred one or two people onto the Continence Nurse since the workshop. We got a list of the Continence nurses there.
- We set up a subgroup for the HSE and meet every three months. There's no change from GPs or public in general though.
- I don't know; it's still embarrassing for younger people, for e.g. if you're 29 and haven't had children and have a continence problem but older people are less embarrassed now.
- We've had a few enquiries but a lot of people working with children are unaware. The people at the workshop were au fait and I wonder did the information get out to the people who really need it?

#### **5. Have you noticed any changes since the start of the Project such as number of referrals or enquiries?**

60% of respondents reported that there had been no changes noticed since the start of the Project. Over a quarter commented that awareness and referrals had increased but that this was not necessarily due to the Project. Other factors influencing readiness to come forward about continence problems included wider media campaigns and professionals' own work with patients and community groups in their area. Tangible changes included training and work with the educational sector as discussed above. A couple of professionals in well established practices said that they had gained little and hoped that the Project could provide information on new innovations, research and developments in treatment and prevention.

- More people are using services and our incontinence leaflet is reprinted more than any other. It's not so much the work of the project but our own work here.
- Leaflets won't do any good, you need one to one contact and follow-up.
- Year on year we have more referrals; people are more aware that something can be done for continence but I'm not sure whether that has anything to do with the project.
- Training for SNAs, the forthcoming journal for secondary schools, contact with our local Continence Advisor and the Paediatric Community Consultant. We're interested in linking in with health promotion to get the information out there.

**6. Have you received the Resource Packs?**

**Table 9** - Resource Packs received

Yes	No
6	18

One quarter of respondents had received resource packs and of the remaining three quarters, almost all requested a pack to be forwarded to them.

**7. How useful have you found the Resource packs? And**

**8. What differences have the Resource packs made to your practice?**

At the time of the evaluation, few people had actually used the pack and comments appreciated having the pack as a resource. This underlines the point that further evaluation in six months could more accurately assess the impact of the packs.

**9. Is there anything else that you would like to be included in the resource packs?**

The following recommendations were made by professionals:

- The need to mention of the continence trained physiotherapists and inclusion of a flow chart like the enuresis diagram so people know what happens with their referral when they go to a clinic.
- Updates on aids and appliances such as disposable items, innovations in catheters and bladder washouts.
- Information on which aids and appliances are available without cost from the health board or at subsidised cost.
- Updates on drug treatments and how the drugs can interact with other medication.
- Information to give to teachers and special needs assistants in schools which could include symptoms and general toilet and bowel care as well as paths to referral.
- Information for consumers and information designed for consumers with special needs such as literacy problems and disabilities.
- The basics on how to find out whether the problem is routine or physical for example.
- Something on how to prevent 'do not attends'; it's a problem particularly for new patients and taboo plays a part; people are embarrassed and anxious and while they don't mind making the appointment with the GP, they don't turn up.

**10. What differences could the restructuring of the health services make to the service?**

- The creation of super-trusts will make it worse. We already have geographical mid-zones, e.g. Omagh, which are more under-resourced than areas which are coping reasonably. Restructuring means more uniformity with our joint continence plan and group which helps to unify things like forms.
- We'll be one big Trust and I think that will dilute the service.

## **11. Issues arising**

The need for ongoing training, training in working with children and adults and children with disabilities, a regular continence conference and in-house training to facilitate lack of staffing were highlighted. Differences between areas in terms of provision were noted with some areas being well resourced while another professional said that there was no private room to assess patients. The need to extend training to care assistants and home helps as well as to professionals working in schools was acknowledged. The role of GPs in referral was interestingly said to be influenced by the lack of business incentives to refer patients on to continence clinics. This was noted to be in contrast with the setting of targets for referral to cancer screening, for example. A number of professionals emphasised that lack of resources was a barrier in providing care, in some places there was no suitable accommodation for patient consultation and that the creation of a Paediatric Continence Advisor post or posts was required.

- The biggest problem is that there aren't enough resources out in the community. People get fed up on the waiting list to see physios and then opt for surgery. It would help if they could see the physio next week. In Australia you get seen quickly; you get it fixed and there's no taboo; something can be done about it. If people see that treatments are quick and work it would help, the message gets around and reduces the taboo if people can say; "I had a problem and it's fixed."
- Until we have the necessary resources there's no point raising awareness; our hands are tied. I welcome anything that raises the profile of continence and I'm grateful to be involved. However, without staff, we're juggling to give a service. It's a case of robbing Peter to pay Paul. I hope that the commissioners will consider the inequity around service provision and access.

- GPs don't refer not because it's taboo but they know the waiting list. Referrals will increase for a while after I do a talk. A bigger issue is that there are no targets for continence for GPs unlike other issues like cervical and prostate screening. GPs are businesses and at present they won't get more money if they do refer. It's not a Government target and it comes from above down; nothing makes them work if they don't have a target. Lobbying is necessary from statutory bodies.
- You could perhaps bring greater awareness to schools via the RSE programme but at present there's no mention even of bladder care.
- We need more things like Continence Awareness week like we have in Derry with stands in shopping centres and information on the local radio. Let people know and have experts on hand to answer queries on the radio.

Comments on the workshop were spontaneously offered by some respondents although more than twelve months had elapsed since it was held.

## 4 DISCUSSION

### Project Performance

One of the greatest achievements of the Project was the workshop held in November 2006, which brought professionals and consumers together to share their views and understanding around issues relating to continence. Not only were people gathered but discussion about the stigmatised and sensitive topic of incontinence was opened with enthusiasm and emotion from workshop participants. The significance of the workshop requires acknowledgement of the efforts of the Project Manager, Project Board and CAWT. As professionals commented:

“I got more information than I’d expected and learned a lot, I liked hearing about the statistics and different medications available.”

“It (*the workshop*) gave information for families and patients. It was useful and gave us a push in the right direction. It’s such a personal thing and it was good to get people talking about continence.”

With regard to the Project objectives, increasing awareness among professionals and making information and support more accessible to professionals were successfully achieved. The achievement of these two objectives are evidenced by the deliverables of the Project; the workshop, visits to more than thirty community and voluntary organisations, the questionnaires and the distribution of the Resource folders. There is evident demand both for more visits and more folders showing that the word is spreading. Consumers appreciated the opportunity to gain information and the postal questionnaires identified that this as a priority with 58% of organisations providing no information at all for consumers. Professionals working in residential settings in particular were appreciative of the work of the Project and commented that they can feel quite isolated and are left to source updates on their own. The theme running through comments, however, was that increasing awareness is a process rather than a product and comprises several aspects including marketing, timing and strategy. One professional remarked;

“There’s more awareness out there and health professionals talk about it more but it’s just the tip of the iceberg.”

The objectives which were considered as most successfully achieved were mapping service provision and identifying gaps in provision which was achieved through the questionnaires and workshop. Particular difficulties were noted with regard to services for adults and children with disabilities. Professionals pointed out the need for specialised training for working with those with physical and sensory disabilities and clients with intellectual disabilities. The ethical issues of working with children around intimate care were also pointed out. Several respondents voiced expectations about establishing the conditions for equity of services yet by the close of the Project, people were alert to the difficulties of achieving this. Restructuring of the health services on both sides of the border was seen as a possible road to greater equity although there was also a concern that continence issues could become lost in the increased competition for resources.

Barriers to increasing awareness among professionals include lack of resources, high workload, low priority of continence issues and the stigma of incontinence. General Practitioners (GPs) were identified as the gatekeepers to continence services and regret was expressed that the Resource folders had not been distributed earlier in the life of the Project to enable full evaluation of their impact. The Project highlighted the differing levels of service delivery in the three geographical areas. It was pointed out that there is no business incentive for GPs to refer to continence clinics because these are not included in rewarded targets unlike referrals for cervical or prostate screening.

Professionals at the workshop who were already working within a well established service were surprised to learn that other areas were less advantaged. The gains offered by the Project were less for this group as they felt that others learned more from them. It is suggested, therefore, that one issue for the future is the provision of continued updating and standardisation of information and training. The postal questionnaire identified the need for a coherent and standardised approach to training

and the need to extend training to more carers, home helps and support groups. Professionals noted a need to extend training in educational settings as initiated by health promotion in Donegal.

The objective of making professional practice more effective was deemed by over half of the Project Board to have been quite successfully achieved. The foundations have been established, for example with initiatives such as joint cross border training and professional forums. The point was emphasised that the Project had made its contribution and that it was now up to the health boards and individuals concerned to continue the work at clinical and organisational levels. Other barriers to improving practice were lack of availability of appliances, aids and new innovations in Ireland and lack of staffing and facilities in some services. On an organisational level, the need for the commissioning bodies and senior management to plan and resource services was underlined.

The facilitation of community support activities was seen as having been successfully supported primarily by the Project Manager's visits. The hard work involved was acknowledged and echoed by professionals interviewed who said that their own efforts to raise awareness always found one to one contact the most effective method. The healthy demand for visits to more groups is evidence to the need and success of this work.

More involvement of consumers and a greater consumer focus in general had been an expectation of the Project which was not borne out to the extent anticipated. The difficulty in contacting consumers for the evaluation may be seen as evidence for this. The involvement of the consumer group Incontact was seen as invaluable for the Project yet the need for adaptation to the health system in Ireland was highlighted. For example, different terms for the relevant professionals are used in England and the aids and methods used may differ from those available in Ireland. Further publicisation of the weblinks and consumer information as well as developing links with the newly founded Irish Continence Foundation was suggested. As the analysis of the postal

questionnaires found, only one in ten organisations give website information to clients therefore this would be a useful resource.

Overall, the Project worked effectively and delivered on time and within their budget. The appointment of an external quality assurance team was a positive contribution. Professional networks had been established which would be continued after the Project. Some felt that the bureaucracy of the PRINCE2 project management system (and documentation requirements) at the start of the Project, however, was a serious setback and appeared to have resulted in the perception of some waste of resources and time. It is recognised, however, that for staff and Project Board members who had not previously used PRINCE2, there would be a steep learning curve. Feedback from the Project Board for the CAWT development centre was that their contribution at the start could have been more constructive in supporting Board members and in establishing workable communication systems. Representatives from the CAWT development centre have reported that it is not uncommon for projects to suffer some ambiguity at the start and to develop clarity as they progress.

### **Project Impact**

In terms of its impact on public awareness, most professionals interviewed felt that, in general, the stigma of incontinence was slowly and patchily eroding in society. Other initiatives such as national Bladder Awareness week and articles in the general press were mentioned as playing their part. Continence issues among younger people and those with neurological disabilities and intellectual disabilities, however, were still felt to be clouded with stigma. This was identified by participants at the workshop (Buckley et al., 2007)<sup>18</sup> who reported that incontinence is often assumed to be a part of having a disability and is often not thoroughly investigated by professionals. Comments highlighted the difficulties inherent in publicising the issue of continence and Board members had seen at first hand the reluctance of the press to give adequate coverage to continence issues. In the same manner as other CAWT projects, a publicity plan was

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<sup>18</sup> Buckley, B., Kennedy, M., & Murphy, M., (2007). Barriers to effective care of continence. Forum, March, 51-54.

developed for the two main project milestones; the November 2006 workshop and the launch of the resources pack in September 2007. For both of those events a news release and publicity photographs were issued to both national and all local media within the geographic remit of the project. However, unlike other CAWT cross border projects events the level of media interest was relatively low. Project Board members contacted local radio stations to highlight continence issues but were not offered a slot. The reason for this rejection was that they would not be presenting any new material despite the fact there was evidence from previous radio discussions in Derry and Donegal that a high number of consumers came forward.

On a highly positive note, a number of actions had been initiated by contact with the Project. These included health promotion in schools, training of Special Needs Assistants in Donegal, inclusion of an article in a schools' health promotion journal and a section on continence in the health section of the Donegal Secondary School Students' Diary which will be included nationally in secondary school student diaries. These developments are highly significant and will enable the information to be filtered into mainstream education and help to open discussion among adolescents for whom the issue of incontinence may be particularly stigmatised. A joint forum took place in January 2008 in Dundalk between the Irish Continence Interest Group and the Northern Ireland group.

The majority of the Board felt that the Project and the time they had spent on it was a good investment for their organisation as a whole. It was felt that the real value cannot be ascertained as yet and will depend on the use of the Resource packs. As a consumer commented:

“It's too early to say what impact the pack has had and I hope people will use it and leave it for others to look at.”

There was concern expressed that the work could be forgotten about against the backdrop of strategic priorities for both health systems.

### **Partnership and Sustainability**

The Project was successful in establishing multi-disciplinary networks, setting up joint professional training and acting as a catalyst through the workshops and visits in initiating developments such as the training for Special Needs Assistants. The objective of facilitating cross border support activities was thought to have been quite successfully achieved through the workshop, the Project Manager's and Project Board's formal and informal networking, organisation of joint training and the planned joint continence focus groups, there was a recognition that these links require further development. One professional commented;

“We're not meeting at all with our counterparts in Donegal although we meet with professionals within Northern Ireland.”

A consumer said that inequality of services is an issue and that cross border working would go a long way to resolve some of this:

“I'd like to pretend the border isn't there. In Donegal, there's difficulty in accessing specialist services; there's no neurologist for example.”

Barriers concerned the difficulties in ensuring standardisation of care across different jurisdictions and areas and lack of resources as well as the low priority of continence issues in general within health care. The postal questionnaire had identified the gate-keeping role of GPs and these could be targeted for further information and training. Cross border working was also felt not to be high on the agenda for health boards and trusts.

The continuation of the work of the Project was felt to be paramount by Project Board, professionals and consumers consulted for the evaluation. Clearly, this involves a number of levels from support from commissioning bodies, resourcing, training strategy and implementation to awareness raising. In order to support this, the creation of a Paediatric Continence Advisor post or posts was felt to be important and was a recommendation from the Department of Health (2000)<sup>19</sup>. With regard to awareness, development of the community visiting programme was felt to be vital as well as

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<sup>19</sup> Department of Health (2000). Good Practice in Continence Services.

involving local and national media and working cross border on awareness raising campaigns such as Bladder Awareness Week.

## 5 Taking the Learning Forward: Issues for Consideration

This evaluation has highlighted the achievements of CASP in mapping continence services and the gaps within services, raising awareness in professionals and consumers, establishing professional multi-disciplinary and cross border networks and acting as a catalyst in improving professional practice.

The continuation of the work of the Project was felt to be paramount by Project Board, professionals and consumers consulted for the evaluation. Clearly, this involves a number of levels from support from commissioning bodies, resourcing, training strategy and implementation to awareness raising.

### **Sustaining and developing the work**

As stated above, there was consensus that the work of the Project needs to be continued. Issues suggested include:

- Funding of a post or posts as appropriate, for example Paediatric Continence Advisor, Physical & Sensory Continence Advisor and Director of Continence Services as per best practice outlined by the Department of Health, UK<sup>20</sup> is suggested.
- Continue to develop a training strategy and business plans which will standardise training, enable updates, and extend training to GPs and allied professionals such as residential and private care homes, social work, home helps and carers and relatives.
- Extend training to include collaborative work with professionals working in education for preventive work in health promotion, as occurring in Donegal and in supporting teachers and classroom assistants to manage continence effectively.
- Target gaps in provision of service and training such as professionals working with people with physical and sensory disabilities and intellectual disabilities and children.
- Gaps in provision include preventive group sessions for post natal women.

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<sup>20</sup> Department of Health (2000). Good Practice in Continence Services.

- Lobby senior management and commissioning bodies in the health services to acknowledge the importance of continence services and develop a cross border approach.
- There is a need to continue to follow up the use of the Resource folders and to update them. This could include a further evaluation of their use.
- The networks established during the Project need to be sustained and developed, for example with regular discussion forums and sharing of training.

### **Involving consumers and increasing awareness**

The Continence Foundation<sup>21</sup> cites that access to quality information about treatment options is one of the important elements to helping people to manage continence. The following recommendations were suggested:

- The involvement of the voluntary support agencies (Incontact, Continence Foundation) needs to be sustained so that professionals and consumers can access information and consumers and their carers gain benefit from advocacy. Online information could be adapted for use in Ireland.
- A need for adaptation of insert information and leaflets issued by UK consumer groups was highlighted. For example, different terms for the relevant professionals are used in England and the aids and methods used may differ from those available in Ireland.
- Further publicisation of the weblinks and consumer information as well as developing links with the newly founded Irish Continence Foundation was suggested. As the analysis of the postal questionnaires found, only one in ten organisations give website information to clients therefore this would be a useful resource.
- A second workshop could be considered to develop the involvement of consumers, carers and voluntary support groups and to plan for action.
- Continue to visit community, voluntary and vulnerable groups.

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<sup>21</sup> Continence Foundation information leaflets available [www.continencefoundation.org.uk](http://www.continencefoundation.org.uk)

- Work with Support agencies e.g. Incontact to develop client and carer information for an Irish context.
- Ensure that consumer information is accessible to those with needs such as literacy problems, physical and sensory disabilities, intellectual and mental health disabilities as recommended by the National Institute of Health and Clinical Excellence (2007)<sup>22</sup> guidelines on the management of faecal incontinence.
- Harness local and national media during health promotion campaigns such as National Bladder Awareness Day and work cross border to pool resources.
- Most fundamentally, there is evidence that consumers are reluctant to approach a continence labelled service. As a professional commented: “Taboo plays a part in non-attendance at appointments; people are embarrassed and anxious and while they don’t mind making the appointment with the GP, they don’t turn up at the continence clinic.’
- Consumers may be more likely, as several respondents suggested, to access services under a general health service dealing with general health issues, such as through Public Health Nurses and Primary Care Nurses who do not specifically carry a continence label.

Feedback on the contents of the Resource pack included recommendations for the following:

- The packs were produced at the latter end of the Project and it would have been desirable to distribute these earlier to enable fuller evaluation of their impact
- Updates on new aids and appliances
- Information on new drug treatments and contra-indications
- Inclusion of continence trained physiotherapists in a flow chart of routes to referral
- Information to give to teachers including symptoms, general toilet and bowel care and paths to referral
- Information for service users, relatives and carers

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<sup>22</sup> NICE (June, 2007). The Management of Faecal Incontinence in Adults, available [www.nice.org.uk](http://www.nice.org.uk)

- Suggestions on how to encourage patients to attend and to minimise non-attendance at appointments
- A list of what aids and appliances are available at subsidised cost or through the health board.

### **Learning for future projects undertaken by the CAWT partnership**

Learning for the Project Board members included the need for:

- Establishment of the Board prior to the start of the Project and before employment of the Project Manager
- Timely training in a project management system such as PRINCE2
- Support with clarification of the Project objectives and measurable outcomes and targets
- Reminder of group processes and stages in group development i.e. norming, storming, performing and adjourning.
- Employment of a trained facilitator could help to make initial meetings more effective

## 6 CONCLUSION

This external evaluation set out to assess the performance, impact and effectiveness of the partnership approach of the Continence Awareness and Support Project. A wider perspective was gained by including the views of Project Board members, consumers and professionals. The findings of the evaluation were very positive although it is cautioned that the sample size, particularly with respect to consumers was small. More comprehensive evaluation of the Resource packs could be enabled by interviewing in another six months when more packs have been distributed and more time has elapsed to assess their impact on professional practice. The majority of the objectives of the Project were successfully achieved within the timeframe and budget and the deliverables of the Project including the workshop, the questionnaires, Resource packs and visits have had a demonstrable impact on raising awareness in professionals and in achieving the objective of mapping services and gaps in service. Secondary impact of the Project can be seen in the initiatives such as the work of training and health promotion in schools in Donegal.

The multi-disciplinary and partnership approach of the Project was successful in that professional networks have been established, discussion forums have been developed involving consumer and support groups and professionals and a joint approach to professional training is being formulated. The achievement of the Project in attaining its objectives against the background of major organisational change in the health services on both sides of the border needs to be recognised.

The call for the work of the project to be sustained was highlighted by all respondents. Having identified gaps and needs for the services, a contribution to a road map for the future in terms of planning an integrated service has been made by the Project. There was recognition that the continence services require more resources such as Paediatric Continence Advisors on both sides of the border as well as specialist Advisors in Intellectual Disabilities and Physical and Sensory Disabilities. The continued lobbying

of the commissioning bodies was also seen to be vital in ensuring a fair, integrated and quality service.

In the words of a consumer: "Don't let the thing die, it will be a long slow process, keep hammering away!"

## Appendix 7.1 Telephone Questionnaire – Project Board

Interview number \_\_\_\_\_

Thank you for agreeing to take part in this evaluation. The questionnaire focuses on four different areas:

- A The achievement of the Project objectives
- B The management structure and how you feel it's been working
- C The next step and sustaining/developing the services
- D Partnership aspects such as cross border and across disciplines and organisation types.

Where questions are not applicable, we will go onto the next question.

### A **Project Objectives**

1. What did you expect the project to deliver on when you set out?
2. What do you consider are the positives or successes of the project?
3. What are the weaknesses of the project?
4. What would you like to have done differently?
5. Do you feel that there have been any changes in awareness or in the willingness of people to ask for help with continence problems since the start of the project?
6. Thinking of the project objectives, could we consider each one and rate the extent to which you feel it has been successfully achieved then look at what you feel are the successes, barriers and ways forward. We'll start with the objective of:

<b>Very Successful</b>			<b>Not Successful</b>
<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>

Objective	4	3	2	1	Explain rating	Barriers	Solutions?
The project has succeeded in identifying service provision on both sides of the border							
Gaps in provision have been identified							
The project has							

increased public awareness							
Awareness among professionals has been increased through the project							
Progress has been made in making professional practice more effective.							
Information and support has been made more accessible c) to professionals d) to consumers							
Community support activities have been facilitated							
Cross border support activities have been facilitated.							

**B Management Structure and Processes**

- 7 Do you have any comments about the effectiveness of the Project Board?
- 8 Do you have any comments about the PRINCE2 approach?
- 9 How well is communication between the different Project Board members working?
- 10 In your opinion, has the Project as a whole been worth the money?
- 11 Has the Project been a good investment for your organisation? Please explain.

**C Developing Services**

12. How would you like the impact of the Project to be sustained? E.g. mainstreaming, continuity planning
13. What changes in behaviours/practice/innovations/business case planning or changes in attitude are happening as a consequence of the Project?
14. Do you have any suggestions for developments that should be taking place?

**D Partnership Aspects**

15. Any thoughts about the collaborative nature of the project in terms of involving organisations from statutory, voluntary, community, industrial sectors/multidisciplinary?
16. How might the cross border links built during the project be supported and developed?
17. How might services be affected by the current re-structuring of health services on both sides of the border?
18. How could support agencies such as Incontact and the Continence Foundation be involved at local level and adapted to local needs?
19. Any other comments?
20. Issues arising

## Appendix 7.2 Telephone Interviews – Consumers

Telephone Interview Number \_\_\_\_\_

**Thank you for contributing to feedback about the Continence Awareness Support Project. All answers are in strict confidence and no names are mentioned. We'll need about 10 minutes for the interviews. If you'd like to know the results of the evaluation, a summary of the results will be posted on the CAWT website.**

What client group are you representing?

Voluntary : MS, Stroke	
Individual consumer	
Children & young people to 18 years	
Older people 65+	
Under 65's	

1. What contact have you had with the Continence Awareness Support Project?

Attended workshop	
Postal questionnaire	
Visit from Coordinator Mary Murphy	
Other – please explain	

2. What difference has your contact with the Project made/ what impact has this had? (e.g. in terms of your organisation, raising general public awareness).

3. What changes would you like to see happening as a result of the Project?

4. What benefits do you feel there are in involving services on both sides of the border?

5. Do you believe that service users should be more involved in the planning of further Projects in continence awareness?

6. Do you have a Resource pack?

Yes	No
1	

7. If no, would you like one to be sent to you?

Check address.

8. How useful do you find the pack is?

9. Is there anything you feel is missed out of the pack?

10. **Any other comments?**

## Appendix 7.3

**Telephone QUESTIONNAIRE –Professionals**

Interview number \_\_\_\_\_

**Thank you for agreeing to take part in this evaluation. No names are used in order to maintain confidentiality. If you'd like to know about the results of all the feedback, a summary will be posted on the CAWT website.**

1. With which client group do you work?

Children and young people under 18	
Adults	
Older people	
Specific group – please state	

2. What is your location?

Derry	
Donegal	
Sperrin & Lakeland	

3. What contact have you had with the Continence Awareness Support Project? Please tick:

Attended workshop	
Postal questionnaire	
Received Resource pack	
Attended launch of Resource pack	
Other – (please state)	

4. What were your expectations of the Continence Awareness Support Project?

5. Were your expectations met?

**Yes / Mostly / A Little/ No**

Please explain:

4. Do you think the Project has had any impact on raising awareness of continence services?

**Greatly / A Little/ Not at all / Unsure**

Please explain:

5. Have you noticed any changes since the start of the project? E.g. number of referrals, enquiries, If so, please specify.

6. Have you received the Resource Packs? **Yes / No**

7. If No, would you like some packs to be sent to you? **Yes / No**

If yes, please include your address in your email.

8. How useful have you found the Resource packs?
9. What differences have the Resource packs made to your practice?
10. Is there anything else that you would like to be included in the resource packs?
11. Any other comments in general?
12. Issues arising, e.g. training needs, gaps in service,

**Thank you for your time and consideration in taking part in this evaluation.**

## **Appendix 7.4**

**Buckley, B., Kennedy, B., & Murphy, M., (2007). 'Barriers to effective care of incontinence.' Forum: Clinical Review, March, 51-54.**