INCONTINENCE: WHY PEOPLE DO NOT SEEK HELP.

Prepared for
Department of Health and Ageing

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The research team for this project comprised:
Jenny Pearson (Project Manager)
Dr Ian Tucker
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Prof Paul Finucane

Dr Jan Paterson provided specialist advice regarding research on under-reporting of continence problems.

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- the many consumers, carers, service providers and their representative organisations who participated in focus groups, questionnaires and interviews for this research project;
- members of the National Aboriginal and Torres Strait Islander HACC Reference Group Continence Sub-Committee and the multicultural continence interest groups and service providers who provided advice on indigenous and multicultural issues;
• the National Expert Advisory Committee for the National Continence Management Strategy and members of the Steering Committee, Associate Professor David Fonda and Pauline Chiarelli;

• Anne McNeill, Marjory Kobold, Christine King and Gouri Gopalakrishnan of the Department of Health and Ageing; and

• Karen Hill and Kathy Larrigy, IDSC Library.
Executive Summary

This research into the reasons for under-reporting of continence problems forms part of the National Continence Needs Analysis. The National Continence Needs Analysis comprises a group of research projects that have been funded by the Commonwealth Government as part of its National Continence Management Strategy.

Project Objective and Methodology

The objective of this project was to report on the reasons why people with continence problems from all major Australian cultures under-report, barriers to treatment, and the training and information requirements of carers and community workers.

The project involved:

- gathering qualitative and quantitative information on reasons for under-reporting of both urinary and faecal incontinence;
- assessing what the cultural, social and physical barriers are to seeking treatment;
- collecting qualitative information about the accessibility and affordability of continence aids and appliances services;
- collecting this information, after appropriate liaison, from major ethnic groups, indigenous communities and rural and remote communities;
- collecting information from carers and community workers about effective means of providing them with relevant information and training in both areas of incontinence; and
- seeking information on what carers, community workers and people with incontinence expect from the National Continence Management Strategy and the service sector.

The research methodology included:

- review of the research literature;
- focus groups with consumers and carers and with service providers;
- surveys of health and community workers, specialist continence practitioners, peak bodies and advocacy groups representing consumers and carers, and members of Aged Care Assessment Teams; and
- individual interviews with key stakeholders.

The research was undertaken by a multidisciplinary project team managed by Jenny Pearson & Associates Pty Ltd.
Key Findings

The key findings of this research project are summarized below.

Review of the Research Literature

Review of the research literature has revealed that at least 50%, and possibly more than 60%, of people who have urinary incontinence do not report this problem to a health practitioner. The rate of reporting may be affected by factors such as age group and the type and severity of incontinence. The under-reporting of faecal incontinence is even higher, with studies indicating that more than 80% of people with this problem have not reported it to a doctor.

The major reasons identified in the research literature for under-reporting of continence problems include:

- assuming that incontinence is normal for their gender and age group;
- not knowing that effective treatment is available;
- being too embarrassed to discuss continence problems;
- considering the continence problem is not severe enough to warrant medical attention;
- fear of surgery; and
- hoping that the symptoms will improve on their own.

Research studies show that in most cases, continence problems (urinary and faecal) can be successfully treated, often without surgery or invasive investigations.

The main suggestions from the research literature for increasing reporting behaviour are:

- encouraging health workers (doctors and nurses) to specifically but sensitively inquire about continence problems during routine health checks; and
- improving public education and awareness to dispel the common myths regarding incontinence ie that incontinence is an inevitable result of ageing and childbirth and that it cannot be treated.

Reasons for Under Reporting of Continence Problems

The results of our consultations have identified reasons for under-reporting of continence problems that are consistent with the findings of the research literature in this area.

The majority of health and community workers, specialist continence practitioners and members of Aged Care Assessment Teams surveyed for this project had experienced reluctance by their clients to disclose continence problems.
By and large, there are three major reasons that appear to account for the majority of under-reporting behaviour evident in all major Australian cultural groups:

- the embarrassment and social taboo associated with incontinence;
- the myths and lack of knowledge about incontinence (for example, the belief that incontinence is a normal part of ageing and an inevitable consequence of childbearing); and
- the reluctance and lack of specific skills of many health practitioners to raise and effectively address this issue with their patients.

Additional concerns were described for elderly people, particularly fear of being placed in residential care if their continence problems were revealed. The carer, rather than the person with the continence problem, is often the one who actually reports the problem to a health worker.

Although there were conflicting accounts regarding the effects of age and gender on reporting behaviour, the general view was that the social and cultural barriers to reporting continence problems were stronger in the older population and in the male gender.

Particular cultural and religious sensitivities in respect of the reporting and management of continence problems were identified.

Our consultations have found that many people are reluctant to approach their general practitioner about continence problems due to a combination of embarrassment, other fears, lack of knowledge about incontinence and treatment options, and considering the problem not sufficiently important to take up the GP’s time. General practitioners and other first line health workers have an important role to play in overcoming these barriers to disclosure and in providing an appropriate response when continence problems are reported to them.

**Access to Continence Services and Treatment**

The service and resource environment may play a significant role in changing people’s attitudes to incontinence, for example by promoting awareness that incontinence can be treated, improved or better managed. The more people who successfully access appropriate and effective continence services and assistance, the further the message is spread that practical help is available. This in turn provides people with a reason to report their continence problems and seek assistance.

The main access issues identified by stakeholders consulted for this research project were:

- inadequate access to continence information and treatment options;
- shortage of continence clinics and trained continence practitioners in some locations, particularly in rural and remote areas;
- travel requirements to access continence treatment deterring treatment seeking;
• high cost of continence pads and other aids and some services including physiotherapy;
• strong concerns from consumer representatives about the adequacy and eligibility requirements of aids and equipment subsidy schemes;
• reported lack of continence services, particularly treatment and rehabilitation oriented services for older people and indigenous Australians;
• reports of long waiting lists for many continence services; and
• information barriers to seeking and accessing continence services for ethnic communities.

**Information Needs**

Most stakeholders consulted for this project recommended a community education campaign to:

• raise community awareness of continence issues and treatment options (ie awareness that ‘something can be done’);
• increase community acceptance of incontinence (removing the ‘taboo’);
• increase peoples’ comfort in talking about their continence problems with health workers; and
• promote prevention, treatment and rehabilitation options (to balance the commercial promotion of pads and products).

The importance of using a range of different media and of having both short and long term promotional strategies was also noted.

Any promotional campaign needs to be coordinated with service providers (including helplines, doctors, continence clinics, community health nurses, etc). Service providers need to be ready to cope with any increased demand resulting from a promotional campaign and service provider attitudes, skills and response to consumer approaches need to match the expectations created by the promotional campaign.

Aboriginal and Torres Strait Islander peoples and those from culturally and linguistically diverse backgrounds have additional needs for culturally appropriate information and resources and for other language translations of continence information.

**Training Requirements**

Training needs in respect of the assessment, diagnosis, treatment and referral of continence problems were identified for a broad range of health practitioners, residential care staff and community workers. There is an urgent need for training of health workers in indigenous communities. A separate project is now underway to develop an appropriate curriculum.
Review of the existing continence training programs available in Australia identified a number of courses available for nurses but a lack of formal training programmes for general practitioners - the health professionals most likely to be the first point of contact for people with continence problems. Despite the availability of continence training programmes for nurses, stakeholders reported a shortage of continence nurse advisers, particularly in rural and remote areas of Australia.

An important aspect of any continence training programme for health professionals should be development of the communication skills and strategies to encourage people who have continence problems to overcome their embarrassment and discuss these problems with the health practitioner.

**Stakeholder Expectations of the National Continence Management Strategy**

The main expectations and priorities for the National Continence Management Strategy identified by stakeholders were:

- Community education and raising public awareness
  - breaking down the taboo
  - demystifying the problem
  - minimizing the stigma
  - letting people know they will get a positive response if they report.
- Educating the health sector to encourage reporting, provide appropriate advice and pay more attention to this issue.
- Providing the resources to meet increased demand flowing from community education (including personnel, equipment, accessible services, and culturally appropriate services).
- Encouraging service providers to be visible and proactive in promoting their services.

**Overall Conclusions**

Our research into the reasons for under-reporting of continence problems and barriers to accessing continence information, services and treatment has identified the following major issues:

- embarrassment, shame and social stigma associated with incontinence appear to presenting a major barrier to the reporting of continence problems for all major Australian cultural groups;
- lack of community awareness and understanding of incontinence and the treatment options, services and supports available, including incorrect perceptions that incontinence is an inevitable result of childbirth and ageing;
- a need for community education and the development of consumer and carer information strategies and resources (including information for indigenous and ethnic communities);
- a need for training and education of health practitioners (particularly general practitioners as a first point of contact), community care workers and residential care
staff in the assessment, treatment, management and referral of people with continence problems; and

- a need to more adequately resource the continence service system, particularly in rural and remote areas, including more effective utilization of existing resources.

The key themes raised by consumer and carer stakeholders during the consultations for this project and supported by service providers were:

- community education and awareness;
- improved training and resources for health workers and continence service providers;
- better information for consumers and carers;
- reduced cost for consumers and carers; and
- improved access to appropriate assessment and treatment of continence problems.

Recommendations

In consultation with representatives of the Commonwealth Department of Health and Aged Care, six major recommendations have been determined to be within the scope of the National Continence Management Strategy. A range of supporting actions to these recommendations are detailed in section 9.0 of this report. It is suggested that the Commonwealth Department of Health and Aged Care through the National Continence Management Strategy takes primary responsibility for coordinating and prioritizing the recommendations, although it is recognized that some recommendations involve responsibilities of state and territory governments.

Recommendation 1
Conduct a staged national community awareness strategy to improve community understanding of incontinence and the options for managing, treating and preventing continence problems, consistent with the aims and strategies outlined in Section 9.1 of this report.

Recommendation 2
Provide improved access to appropriate continence information for consumers and carers with reference to the strategies suggested in Section 9.2 of this report.

Recommendation 3
Develop and promote continence information, resources, training and services for indigenous communities with consideration of the strategies suggested in Section 9.5 of this report.
Recommendation 4
Extend the reach of continence services, programmes and community awareness strategies into ethnic communities with reference to the suggestions contained in Section 9.6 of this report.

Recommendation 5
Facilitate the education and training of health professionals, particularly general practitioners, in respect of assessment, treatment and management of continence problems, using the strategies suggested in Section 9.7 of this report where appropriate.

Recommendation 6
Facilitate improvement in the identification, assessment and where appropriate, referral of continence problems by encouraging local collaboration between general health practitioners and continence practitioners and by encouraging health practitioners to incorporate continence assessments in routine health screenings for women and men.

Priorities for Action
It is recognized that the depth and breadth of the recommendations may require a lengthy period of implementation and so the research team suggests the following areas as priorities for action:

- Changing community attitudes towards, and knowledge of, incontinence.
- Improving access of consumers and carers to appropriate, accurate and relevant information about incontinence.
- Developing the knowledge, skills and clinical practice of general practitioners, with particular attention to the skills required to increase reporting of continence problems.

Issues Beyond the Scope of the National Continence Management Strategy
A number of important issues and suggestions raised by stakeholders during consultations were considered to be beyond the scope of the National Continence Management Strategy. Nevertheless, it is recommended that these suggestions be referred by the Department of Health and Aged Care and the National Continence Management Strategy to appropriate forums for further action or investigation. These issues are:

a) Stakeholder concerns regarding the costs of continence management and limitations in the aims, target groups, eligibility criteria and the level and type of assistance provided through continence aids and equipment schemes.

b) Lack of access to continence assessment, management and treatment options for consumers and carers, particularly in rural and remote and indigenous communities and in residential aged care facilities.

c) Availability and eligibility criteria for home modifications assistance related to continence and hygiene care.
National Continence Management Strategy
Research into Reasons for Under Reporting of Continence Problems

d) Development and implementation of a national rating system for continence pad absorbency.

e) Design features and facilities that could be incorporated in existing and new public toilets to assist consumers and carers to manage continence problems.
1.0 Introduction

This is the Report of the National Continence Needs Analysis project Research into the Reasons for Under Reporting of Continence Problems. This report details:

- the project background and requirements (Section 1);
- the research methodology (Section 2);
- overview of the research literature (Section 3);
- results of stakeholder consultations in respect of reasons for under-reporting (Section 4);
- issues of access, affordability and barriers to continence services and treatment (Section 5);
- information and community education needs (Section 6);
- training needs (Section 7)
- stakeholders’ expectations of the National Continence Management Strategy (Section 8); and
- conclusions and recommendations (Section 9).

1.1 Project Background

The National Continence Needs Analysis comprises a group of research projects that have been funded by the Commonwealth Government as part of its National Continence Management Strategy.

The aims of the National Continence Management Strategy are to:

- reduce admission to residential aged care facilities by improving the treatment and management of incontinence in older Australians; and
- prevent the development of continence problems through preventative strategies and health promotion initiatives targeting younger adults at risk of developing incontinence including women of child bearing age and the general community.

1.2 Project Objectives

The objective of this project was to report on the reasons why people with continence problems from all major Australian cultures under-report, barriers to treatment, and the training and information requirements of carers and community workers.

The project consultants were required to:

- gather qualitative and quantitative information on reasons for under-reporting of both urinary and faecal incontinence;
- assess what the cultural, social and physical barriers are to seeking treatment;
• collect qualitative information about the accessibility and affordability of continence aids and appliances services;

• collect this information, after appropriate liaison, from major ethnic groups, indigenous communities and rural and remote communities;

• collect information from carers and community workers about effective means of providing them with relevant information and training in both areas of incontinence; and

• seek information on what carers, community workers and people with incontinence expect from the National Continence Management Strategy (NCMS) and the service sector.

The key outputs required for this project were:
• a report on the reasons why people with continence problems from all major Australian cultures under-report;

• a list of barriers to treatment; and

• a report on the training and information requirements of carers and community workers.

1.3 The Research Team

This research project was undertaken by Jenny Pearson & Associates Pty Ltd. The research team comprised:

• Jenny Pearson (Managing Director of Jenny Pearson & Associates Pty Ltd) who was the consultant’s project manager for this assignment;

• Dr Ian Tucker (Senior Visiting Medical Specialist, Gynaecology/ Urogynaecology, at the Royal Adelaide Hospital);

• Dr John Bolt (Urologist in private practice and Visiting Medical Specialist, Urology, at the Royal Adelaide Hospital);

• Shayne Kelly (Clinical Nurse Consultant, Continence, with the Royal District Nursing Service of South Australia);

• Susanne Eastwood (Clinical Nurse Consultant, Continence, with the Royal District Nursing Service of South Australia); and

• Professor Paul Finucane (Professor of Rehabilitation & Aged Care and Assistant Dean of the Graduate Medical Course at the Flinders University of South Australia – until February 2001).

Dr Jan Paterson (Flinders University, South Australia) provided advice to the consulting team in respect of under-reporting of incontinence.
2.0 Research Methodology

The research methodology used for this project is summarised in the following diagram and then discussed in more detail.

Continence Needs Analysis - Part Four
Reasons for Under-Reporting of Continence Problems

Project Start-up
- Identification of key stakeholders
- Initial liaison with key stakeholders
- Identification of other information sources
- Development of Consultation Plan

Stakeholder Consultation
- People with incontinence
- Carers
- Community workers
- Health workers
- Ethnic groups
- Indigenous communities
- Rural and remote communities

Focus Groups

Questionnaires

Interviews

Barriers to Seeking Treatment
- Cultural
- Social
- Physical
- Other

Accessibility and Affordability of Continence Services

Information and Training Needs

Stakeholder Expectations of the NCM Strategy and the Service Sector

Analysis of Qualitative and Quantitative Data on Reasons for Under-Reporting

Submissions

Review of Other Information & Research on Under-Reporting

Preparation and Submission of Reports

Mar 2000
Apr 2000
May 2000
Aug 2000
Sep 2000
Jan 2001
2.1 Project Management

A detailed project plan (including project objectives, terms of reference, agreed methodology, work plan, timetable, deliverables, roles and responsibilities, quality management plan and risk management plan) was prepared at the outset of the project and submitted to the Department and Expert Advisory Committee for approval. (The National Continence Management Strategy is guided by an Expert Advisory Committee which has established Project Steering Committees to oversight major projects.) This project plan was then used to guide project activities and timelines.

Ethical issues were also given early attention and ethics approval was sought and obtained from the Research and Ethics Committee of the Repatriation General Hospital, Daw Park, South Australia. All consultation tools, including project information sheets and questionnaires were submitted to this Committee for approval prior to use and letters of authorization from both the Research and Ethics Committee and the Department of Health and Aged Care were distributed with all project correspondence to stakeholders.

The research team liaised on a day to day basis with the Department’s Project Officer and submitted monthly progress reports to the Department, Steering Committee, and National Expert Advisory Committee for the National Continence Management Strategy.

Members of the Steering Committee and Expert Advisory Committee provided valuable feedback and advice in respect of consultation tools and research issues throughout the research project.

The project commenced in April 2000 and consultations were started following ethics approval in June 2000. Receipt of data from questionnaires was closed off at the end of January 2001 to enable preparation of the Final Report.

2.2 Stakeholder Consultation

Given the requirement of this project to canvass the needs of a range of age, gender and cultural groups, the methodology aimed to consult widely with a broad cross-section of consumer, carer and service provider stakeholders.

In view of the sensitive nature of the research topic and the requirements for privacy, confidentiality and informed consent, the researchers did not approach individual members of the general public directly for consultation or research purposes. The strategy used was to provide a range of community and representative organisations with information about the research project and an invitation for any interested individuals to participate if they wished in the range of consultation opportunities provided. These opportunities included:

- attendance at a focus group;
- participation in a confidential telephone interview (a national Freecall number was supplied);
- completion of written questionnaires; and
• forwarding issues to the research team by Reply Paid post, fax or e-mail.

In addition to specific peak bodies and representative organisations, information was provided to community organisations such as the RSL, Country Women’s Association and Bowling Clubs. The RSL in New South Wales participated by placing a notice in their magazine and several members responded to the offer of a confidential telephone interview.

By using several forms of consultation with a range of stakeholder groups, the methodology aimed to provide stakeholders with more than one opportunity to contribute information to the project and to ensure that they had at least one form of consultation with which they felt comfortable. Access to the project for people in remote areas and people from non-English speaking backgrounds was also considered important.

Key stakeholder groups involved in consultations included:
• people with incontinence;
• unpaid carers (for example family members);
• community workers;
• health workers;
• members of Aged Care Assessment Teams (ACATs);
• peak bodies and advocacy groups;
• providers of continence services, products and information (these included continence foundations, district nursing and domiciliary care services, independent living centres, and disability equipment and appliances schemes);
• government funders of continence services;
• specialist continence practitioners; and
• researchers in this field.

Great care was taken to preserve the privacy and confidentiality of individuals participating in the research and names and contact details were not requested or recorded.

**Interviews**

Interviews were conducted with a range of stakeholders throughout the project. Interviews included standard questions for particular stakeholder groups and more targeted interviews in respect of specific project components where appropriate. (Refer Appendix A)

Both face to face and telephone interviews were used.

An initial round of interviews was conducted in the first stage of the project, across all stakeholder groups. The purpose of these interviews was to make contact with key
stakeholders, identify key issues, research and potential sources of information, and refine the subsequent broader consultation and research activities.

Interviews with a wider range of stakeholders continued throughout the project.

Written summaries of all interviews were documented on standard proformas.

**Questionnaires**

Following the initial round of interviews, questionnaires were designed and distributed to the following groups:

- health and community workers (including community/district nurses and general practitioners);
- peak bodies and advocacy groups;
- specialist practitioners in areas related to continence (such as continence nurse advisors, urologists, urogynaecologists and specialist physiotherapists); and
- members of Aged Care Assessment Teams (ACATs) – This questionnaire also included questions relating to Part 2 of the National Continence Needs Analysis investigating incontinence as a factor in admission to residential aged care.

A separate questionnaire was designed for each of the above groups, although the questions followed the core terms of reference for the project. The questionnaires asked about:

- under-reporting of continence problems;
- barriers to accessing continence information, services and treatment (including cultural factors);
- affordability and other access issues;
- information and training needs for consumers, carers and service providers;
- strategies for promotion of continence information; and
- awareness and expectations of the National Continence Management Strategy.

Questionnaires included a range of multiple choice, Likert scale ratings and open-ended questions. (Refer Appendices B, C, and D)

A reply paid facility was provided for return of completed questionnaires.

The questionnaires were distributed through a range of organisations, including:

- recognized peak bodies, advocacy agencies and other representative organisations;
- all Divisions of General Practice across Australia;
- community nursing and district nursing organisations in each state and territory;
- professional bodies and colleges;
• a network of Aged Care Assessment Teams across Australia;
• selected community health centres, women’s health centres, Aboriginal and Torres Strait Islander clinics and migrant health centres; and
• participants at the Continence Foundation of Australia’s 2000 national conference.

The response to the latter distribution was unfortunately poor, and so a supplementary mailout of the Specialist Continence Practitioner questionnaire was conducted to all members of the Nursing for Continence Interest Group in South Australia with a better response achieved. This process was not extended to other jurisdictions due to project time frame limitations.

The total sample size for distribution of the questionnaires exceeded 400 practitioners and organisations. The total number of questionnaires cannot be confirmed as some organisations and peak bodies copied the questionnaires and further distributed these among their constituents. The number of completed questionnaires returned appears below:

Questionnaire for Health and Community Workers 66
Questionnaire for Aged Care Assessment Team Members 107
Questionnaire for Specialist Continence Practitioners 15
Questionnaire for Peak Bodies and Advocacy Groups 24

**Total Returns** 212

The professional groups represented in these returns are shown below:

<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged Care Nurses (ACATs and staff of aged care facilities)</td>
<td>57</td>
<td>30.0%</td>
</tr>
<tr>
<td>Community/District Nurses</td>
<td>38</td>
<td>20.0%</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>24</td>
<td>12.6%</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>19</td>
<td>10.0%</td>
</tr>
<tr>
<td>Social Workers</td>
<td>17</td>
<td>8.9%</td>
</tr>
<tr>
<td>Continence Nurses</td>
<td>13</td>
<td>6.8%</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>12</td>
<td>6.3%</td>
</tr>
<tr>
<td>Geriatricians</td>
<td>8</td>
<td>4.2%</td>
</tr>
<tr>
<td>Urologists</td>
<td>2</td>
<td>1.1%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>190</td>
<td>100%</td>
</tr>
</tbody>
</table>

Note: 2 respondents cited more than one professional category. In three cases, questionnaires were completed on a team basis by a group of people, however these are still counted as one return.
Seven of the General Practitioners responding to the Health and Community Worker questionnaire were located in rural areas as were many of the community nurses and ACAT members.

Questionnaire respondents were not asked to identify themselves or the name of their service. In the 57% of returns where location could be identified, the state/territory representation was as follows:

<table>
<thead>
<tr>
<th>State/Territory</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>0%</td>
</tr>
<tr>
<td>New South Wales</td>
<td>15%</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>1%</td>
</tr>
<tr>
<td>Queensland</td>
<td>33%</td>
</tr>
<tr>
<td>South Australia</td>
<td>14%</td>
</tr>
<tr>
<td>Tasmania</td>
<td>2%</td>
</tr>
<tr>
<td>Victoria</td>
<td>24%</td>
</tr>
<tr>
<td>Western Australia</td>
<td>11%</td>
</tr>
</tbody>
</table>

The 24 organisations responding to the *Questionnaire for Peak Bodies and Advocacy Groups* represented a range of stakeholders, including:

- people with disabilities;
- carers;
- people with Multiple Sclerosis;
- people with brain injury;
- people with spina bifida and hydrocephalus;
- elderly people;
- people with physical disability, including paraplegia or quadriplegia; and
- people with Alzheimer’s Disease and other dementias.

The above organisations were based in a range of jurisdictions, including South Australia, Tasmania, Western Australia, New South Wales, Queensland, Victoria, ACT, Northern Territory and some had national representation.

It was originally intended to also survey continence information and continence appliance providers around Australia. However, two other National Continence Management Strategy projects (the Service Directory and Consumer Guide projects) were concurrently...
distributing survey forms to these providers. In order to avoid ‘overloading’ and confusing these providers, our consultation method was changed to telephone interviews and these were conducted towards the end of the Part IV project timeline, well after the other project surveys were completed. Some of the providers also participated in focus group consultations.

**Focus Groups**

Focus groups were conducted with:

- consumer groups (ie people who have continence problems, their carers and organisations representing special needs population groups);
- community workers and health workers; and
- continence service providers.

The focus groups used a discussion group format, introduced by information about the project methodology and confidentiality provisions. Participants were invited to discuss and make comments and suggestions in respect of key issues and questions relevant to the objectives of the project. (Refer Appendix E)

Participants’ comments and suggestions were written on an overhead slide display as participants spoke and participants were able to have their comments and suggestions changed or extended as the focus group progressed.

The focus groups were held in Adelaide, Melbourne, Sydney and Darwin.

Key topics for discussion with the focus groups included:

- location and type of existing continence services;
- information available to consumers about these services;
- reasons for under-reporting of continence problems;
- barriers (cultural, social, physical and other) to accessing continence services and treatment;
- accessibility and affordability of continence services;
- information and training needs (for consumers/carers and service providers); and
- expectations of the National Continence Management Strategy and of the service sector.

Three focus groups for consumers and carers, three for service providers and one combined focus group were conducted.
Strategies for Consulting Special Needs Groups

The project required particular consideration of the needs of people from a range of cultural backgrounds and issues for other special needs groups, such as those living in rural and remote areas and people with types of disability likely to result in continence problems were also important. A number of strategies were used to ensure that the needs of these groups were identified, including:

- presentation to and discussion session with a national meeting of multicultural continence service providers in Melbourne in the preliminary stage of the project;
- two discussion groups conducted with multicultural continence providers in Adelaide and Brisbane to specifically explore cultural issues associated with under reporting of incontinence and access to information and services;
- discussion session with the HACC Aboriginal and Torres Strait Islander Continence Sub-Committee in Darwin;
- interviews with migrant health service and multicultural health workers;
- liaison with Aboriginal health workers and others involved in continence-related initiatives for Aboriginal and Torres Strait Islander people;
- targeting of questionnaires to specific disability organisations; and
- inclusion of rural and remote community health services, ACATs and general practitioners in questionnaire processes.

2.3 Review of other Information and Research on Under-Reporting

In addition to consulting relevant stakeholders, the project team also reviewed relevant research literature and other sources of information in respect of under-reporting of incontinence and barriers to accessing continence services. (Refer Section 3.0)

2.4 Collection of Data on Reasons for Under-Reporting

Specific questions were included in interviews, focus group discussion topics and questionnaires regarding possible reasons for under-reporting of continence problems. Issues explored here included:

- cultural issues;
- gender differences;
- general access to health and allied health services;
- consumer knowledge and access to continence information;
- health worker and community worker training and awareness; and
- availability of continence products and appliances.

The research team’s information gathering and analysis also explored potential strategies to increase reporting of continence problems.
2.5 **Barriers to Seeking Treatment**

The research team also sought to identify and explore a range of cultural, social, physical and other barriers to reporting incontinence and seeking treatment. In addition to identifying barriers, the analysis considered potential strategies for overcoming these.

2.6 **Accessibility and Affordability of Continence Services**

The research team was required to examine access to, and affordability of, continence assessment, treatment and appliances. Issues investigated included:

- cost to the consumer of continence appliances;
- availability of continence information and resource services in all jurisdictions;
- eligibility criteria for programs and services;
- cultural and social access issues; and
- access for people in rural and remote areas.

2.7 **Identify Information and Training Needs**

The research canvassed the information and training needs of:

- people who have incontinence and carers;
- community workers and health workers (including general practitioners); and
- continence service providers.

Information was collected through the various stakeholder consultation strategies and some targeted interviews were conducted.

A range of information needs were investigated, such as:

- consumer and service provider awareness of treatment and resource services;
- differences in information needs across various cultural and socio-economic groups;
- the nature of information that is required;
- the most effective formats and media for information; and
- the best means of distributing information.

The training needs analysis focussed on three major areas:

- the community education and individual training needs of people with incontinence and carers;
- the training needs of professionals who provide continence assessment, management and treatment services; and
- the training needs of community and health workers who do not have a specific focus on continence but may be required to advise or refer on these matters from time to time.
The analysis included:
- an overview of existing training for a range of professional and other groups;
- identification of training resources (human and technical) that may be available to provide training;
- recommendations about the basic curriculum content for training packages/programs; and
- the most effective means of delivering training on continence issues to the various stakeholder groups.

2.8 Identify Stakeholder Expectations of the Strategy

The project interviews, questionnaires and focus groups included specific questions in respect of stakeholder awareness and expectations of the National Continence Management Strategy and expectations of the service sector.

2.9 Analysis and Reporting of Data

The consultation and data collection methods used for this project resulted in extensive qualitative data in the form of comments, issues and suggestions from focus groups, interviews, questionnaires and submissions. The structure of the data collection tools (including focus group questions, interview proforma, etc) enabled all response information to be grouped under specific subject areas and terms of reference.

Where appropriate, direct transcripts of stakeholders’ comments are used in this report’s description of stakeholder issues and concerns, rather than the consultant’s interpretation of these.
3.0 Overview of the Research Literature

A review of the research literature regarding the reasons for under-reporting of urinary and faecal incontinence was undertaken for this project. An overview of this research literature is presented below.

It is firstly notable that the published research literature on the subject of under-reporting of incontinence and the reasons for this under-reporting is not extensive. Although the prevalence of incontinence has been the subject of many studies that often acknowledge the probability of under-reporting, there has been little in the way of specific research investigating why people with incontinence fail to tell their doctors or other health workers. Variations in the definitions of incontinence used in these studies also make cross study comparisons difficult.

3.1 Prevalence of Incontinence

**Urinary Incontinence**

It is estimated that up to 960,000 adults in Australia experience regular or severe urinary incontinence (Millard, 1998). Other researchers have estimated the prevalence to be a little lower, ie up to 900,000 (Shapiro and Setterlund, 2000).

Millard’s 1983 postal survey of randomly selected households in the Sydney region of Australia found that 23% of respondents admitted to some degree of day-time urinary incontinence during the previous three months and 17% also had night-time incontinence. The majority of those reporting urinary incontinence problems were female. (Millard, 1998)

Millard identified a high prevalence rate (over 40%) in the over 60 years age group and also found that elderly people tended to suffer more severe and more frequent episodes of urinary incontinence than young people, with a rising incidence of urge incontinence in the elderly. The first child and pregnancy doubled the prevalence of incontinence in women from 20% to about 40%, with no further change until the fourth child when prevalence rose to 56%. Millard concluded that women experience a high incidence of incontinence throughout their lives but men tend to become incontinent when they are older. The male:female ratio of people with incontinence is a fairly constant 1:2.7 until the age of 60, but changes to 1:1 thereafter.

Millard’s prevalence findings are supported by a number of other studies. The prevalence of urinary incontinence in adults has ranged from 8.5% to 41% in general practice-based studies (Thomas et al, 1980; and Jolleys, 1988). Lara & Nacey (1994) estimated that approximately one third of women in Wellington, New Zealand between the ages of 18 and 40 were incontinent of urine and that urinary incontinence is not just a problem for older multiparous women.

A more recent Australian study (MacLennan, 2000) involved a representative population through the 1998 South Australian Health Omnibus Survey. This study involved
interviews of a randomly selected, cross-sectional sample of 3,010 men and women aged 15 to 97 years. The interviews were conducted in the respondents’ homes by trained female interviewers. MacLennan’s study found that the prevalence of all types of self-reported urinary incontinence in men was 4.4% and in women was 35.5%. The presence of urinary incontinence was more commonly reported in nulliparous women than in men and increased after pregnancy according to parity and age. For example, nulliparous women experienced stress incontinence four times more often than men (10.9% and 2.5% respectively). Increased parity after the first child was not significantly associated with the further risk of pelvic floor dysfunction.

Contrary to a commonly held belief, MacLennan’s study found that caesarean delivery was not associated with significant reduction in long term pelvic floor morbidity when compared with spontaneous vaginal delivery, however there was a significant reduction when caesarean delivery occurred instead of instrument delivery. Other factors found to be associated with pelvic floor problems in this study were age, body mass index, coughing, osteoporosis, arthritis and reduced quality of life scores.

Pinnock and Marshall (1997) also used the South Australian Health Omnibus Survey to investigate the presence of lower urinary tract symptoms (ie the presence of storage and voiding symptoms based on the International Prostate Symptom Score Questionnaire). The study sample comprised 1,204 men and 1,686 women aged over 18 years and living in metropolitan and rural communities of South Australia. This study found that 26% of men and 39% of women of all ages and 48% of men and women over the age of 65 had one or more troublesome lower urinary tract symptoms. The most common of these were nocturia and frequency. Urinary problems to the extent of wet underclothes were identified in 0.7% of the men and 6.0% of the women.

Further Australian research has been conducted by Chiarelli et al (1999) who reported on analysis of the baseline questionnaire data for the Women’s Health Australia project. Their analysis of continence-related questionnaire items revealed a prevalence of urinary incontinence (experienced leaking urine in the past year) in 12.8% of young women (18–23 years), 36.1% of mid-age women (45–50 years) and 35% of older women (70–75 years). The study noted strong associations between constipation, parity, body mass index and urinary incontinence.

Overseas prevalence studies of women living in the community and aged from 19 to 79 years have found that between 24.5% and 27.7% have urinary incontinence and 3.5% to 6.6% have at least daily incontinence episodes. (Rekers et al, 1992; Samuelsson et al, 1997; Turan et al, 1996; Simeonova & Bengtsson, 1969, cited by Lara & Nacey, 1994) In 1969, Wolin surveyed 4,211 nulliparous nursing students aged between 18 and 35 years and found that 50.7% had some degree of stress incontinence. Notably, none of these students had reported their incontinence to a GP (cited by Wellings, 1988).

Shapiro and Setterlund (2000) surveyed 339 older women in Queensland and New South Wales (average age 66 years). They reported that 56% of these women had experienced
unwanted urine loss in the previous 3 months and 31% of these experienced unwanted urine loss more than once per day.

In elderly Australians, the prevalence of urinary incontinence is estimated to be at least 15% and possibly over 30% amongst those living in the community and probably over 50% amongst those living in Australian nursing homes. This figure rises to over 75% if dependent incontinence, (ie not able to get to the toilet without assistance) is considered. (Fonda, 1990; Ouslander et al, 1982). Incontinence has been identified as an important factor in the institutionalization of older people, and elderly people who have urinary incontinence are more likely than their continent peers to be living in nursing homes than in hostels or in the community. (Refer to the National Continence Needs Analysis, Part 2, Report on the Incidence of Incontinence as a Factor in Admission to Residential Aged Care, Jenny Pearson & Associates Pty Ltd, 2001 for further details).

The wide variation in prevalence rates found in various studies has been recognized (for example, Rekers et al, 1992). The reasons for this variation may lie in the use of different definitions of incontinence, different methods of identifying incontinence and sample selection.

In the general population of adult males, the prevalence of urinary incontinence may range from under 2% in the 15 to 64 year age group to around 7% for over 65 year olds (Thomas et al, 1980). The incidence of urinary incontinence is higher for some groups of men, for example, following prostate surgery. Research findings have ranged from 65.6% incidence of incontinence immediately following radical prostatectomy (Kao et al, 2000) to 20% of men incontinent at 12 months (Donnellan et al, 1997) and 8% of men incontinent at 2 years following radical prostatectomy (Steiner et al, 1991). The length of time elapsed since surgery and the type of surgery performed are important variables in these post-prostatectomy outcomes.
Faecal Incontinence

The prevalence of faecal incontinence has been estimated to be at least 1% to 2% of the population. MacLennan’s (2000) study using South Australian Health Omnibus Survey data found the prevalence of flatus and faecal incontinence was 6.8% and 2.3% in men and 10.9% and 3.5% in women, respectively. A survey of people in Wisconsin found that 2.2% admitted to faecal incontinence (Nelson et al, 1995).

In elderly Australians, the prevalence of faecal incontinence is estimated to be between 3% and 9%, increasing to between 10% and 30% for residents of nursing homes. (Refer to the National Continence Needs Analysis, Part 2, Report on the Incidence of Incontinence as a Factor in Admission to Residential Aged Care, Jenny Pearson & Associates Pty Ltd, 2001 for further details).

O’Brien (1998) suggests that the most common cause of faecal incontinence is the trauma of childbirth. Millard (1994) notes that chronic constipation and faecal impaction in particular, may result in urinary and faecal incontinence. Nelson et al (1995) also suggest that causes other than childbirth must be at play, given the high prevalence of faecal incontinence in men (47% of those reporting faecal incontinence in Nelson’s study were men). MacLennan (2000) suggests that genetic predispositions to connective tissue and structural disorders and/or oestrogen deficiency, may link to the persistent associations found between osteoporosis, arthritis and major pelvic floor disorders, including faecal and urinary incontinence. Much of the research that has been done, however, has focused on women following childbirth.

A study of women attending a urogynaecologic outpatient clinic in a maternity hospital in Israel found a prevalence of faecal incontinence of 29%. Of those reporting faecal incontinence, 30% (i.e. 9% of the total study population) were incontinent of solid faeces, 22% (6%) liquid faeces, and 48% (14%) gas. A progressive rise in the prevalence of faecal incontinence was found as patients became older. (Gordon et al, 1999)

In a study of women who had a routine vaginal delivery, Sultan et al (1993) found that 13% of the primiparous women and 23% of the multiparous women had anal incontinence or faecal urgency six weeks after delivery. Thirty five per cent (35%) of the primiparous women had a sphincter defect on endosonography at six weeks.

Mellerup et al (1998) found that 42% of women have anal incontinence following tears of the anal sphincter associated with childbirth, although the majority of these women report stress-provoked incontinence of flatus and loose stools only.

A 1996 study by Walsh et al, involving 81 women who had undergone primary repair of a third degree obstetric tear, found that 37% of these women had an abnormal anorectal examination result, 7% were incontinent of faeces and 12% were incontinent of flatus only.
MacArthur et al (1997) interviewed 906 women at a mean of 10 months following delivery in a Birmingham maternity hospital. They found that 36 women (4% of the study sample) had developed new faecal incontinence after the latest birth and 22 of these women had unresolved symptoms. (This study did not include incontinence of flatus). Although 27 of the women were experiencing faecal incontinence symptoms several times a week, only five of them had consulted a doctor about this problem. MacArthur et al concluded that “Faecal incontinence as an immediate consequence of childbirth is more common than previously realized, and medical attention is rarely sought.” (p46)

The true prevalence of faecal incontinence is uncertain due to a lack of appropriately designed research studies and reluctance of patients to report these symptoms (Leigh and Turnberg, 1982). Research studies in this area are scarce and the subjects of studies are often drawn from highly specific populations, for example, women attending specialist clinics. This can make extrapolation of faecal incontinence prevalence rates to the general population an unreliable proposition. Research involving general community populations, such as MacLennan’s (2000) study are beginning to address this deficiency.

3.2 Reporting Behaviour

There is growing awareness that the true prevalence of urinary and faecal incontinence may have been significantly underestimated, particularly where research data is dependent on patients disclosing this information. It should be noted that much of the research data on the extent of, and reasons for, under-reporting of incontinence has come from prevalence studies that were not specifically designed to explore this issue in detail.

Fultz and Herzog (1993) identified a number of potential validity problems in surveys that rely on self-report of incontinence and suggested that research of this nature may underestimate the prevalence of continence problems. The focus groups they conducted with incontinent older adults suggested difficulties in identifying, remembering, and reporting incontinence. The authors made a number of suggestions for improving the accuracy and validity of survey data, including “setting the stage” before asking questions about incontinence, ensuring respondents are convinced of the legitimacy and importance of the research and specifying a relatively short time frame for reporting the frequency of urinary incontinence. Mitteness (1987) also noted the inherent difficulties of conducting community surveys on embarrassing topics such as incontinence.

Under Reporting of Urinary Incontinence

Millard (1998) reported that only 30% of 301 respondents to a postal survey who had experienced urinary leakage had ever sought treatment for their problem. It was suggested that this low proportion might be partly due to the minor nature of the problems reported by the majority of incontinent respondents (ie infrequent and/or small amounts of leakage). Millard found that the elderly (those aged over 60 years) and blue-collar or unemployed people were most likely to seek help. This coincided with higher prevalence rates and more severe degrees of incontinence found in these groups. Of those with ‘significant incontinence’ (ie more frequent and severe leakage), only 40%
had ever sought treatment. Thirty per cent of males and females had seen their GP about their incontinence, while 30% of men and 17% of women had seen a specialist.

Pinnock and Marshall (1997) investigating the broader area of lower urinary tract symptoms in a South Australian population sample, found that only 28% of men and 27% of women with troublesome lower urinary tract symptoms saw a doctor about their problem. Although these researchers found a significant association between visiting the doctor and symptom prevalence and dissatisfaction with the urinary conditions, 63% of men and 59% of women who were dissatisfied with their condition did not seek medical help.

Further Australian research found that while 64% of women experienced incontinence during pregnancy and 20% found this problem quite bothersome, only 23% had spoken with a healthcare professional about the problem. (Chiarelli and Campbell, 1997).

Reporting rates may be even lower for Aboriginal women. Benness and Manning (1999) found that only 16% of a sample of Aboriginal women with incontinence had sought help.

Brown et al (2000) asked incontinent Australian women who reported leaking urine ‘often’ or ‘always’ and had not sought help, why they had not sought assistance. The sample comprised 241 young women, aged 21-26 years, 415 mid-age women, aged 48-53 years and 395 older women, aged 72-79 years. The most common reasons given by the young women for not seeking help were:

- don’t consider it a problem (44.8%);
- feel I can manage on my own (40.2%);
- too embarrassed (21.2%);
- think it will go away by itself (15.4%); and
- don’t know what to say (11.2%).

Amongst the mid-age and older women, the most common reasons for not seeking help were:

- feel I can manage on my own (25.1% and 30.4% respectively);
- don’t consider it a problem (11.6% and 10.6%);
- afraid they will recommend surgery (12.0% and 7.3%);
- too embarrassed (7.7% and 6.1%); and
- don’t know what to say (3.9% and 1.5%).
Other reasons given across all the selected age groups included:

- don’t know who to ask for help;
- want to see a female but none available;
- too busy; and
- long waiting time for an appointment.

Prosper and Dobbs (1997), citing O’Brien et al (1991), estimated that fewer than one third of regularly incontinent women aged 20 to 60 years had reported their problem to a GP or nurse. Prosper and Dobbs’s own study of over 75 year olds found that only 45% of those who had ever experienced urinary incontinence had reported the problem. Of those experiencing daily urinary incontinence, 61% had discussed their problem with a health professional.

Hart et al (1999) undertook a survey by standardized questionnaire using a random sample of women employed full-time at an urban university. The median age of the 1,113 women who responded was 39 years and 21% of these women reported monthly or more frequent urinary incontinence. (Urinary incontinence for this study was defined as a positive response to any of the following questions: “Have you ever lost urine when you were not able to get to the toilet in time?”; “Have you ever lost urine when you were asleep?”; “Have you ever lost urine when you laugh, cough or sneeze?”; “Have you ever lost urine at any time not mentioned above?”.) Only 46% of the women with monthly or more frequent urinary incontinence had reported this problem to a doctor or nurse. The authors reported that the most common reason for not seeking help with urinary incontinence was that the women thought that this was a normal problem for women of their age. Hart et al also noted the findings of Reymer and Hunskaar (1994) that 82% of perimenopausal women (aged between 40 and 50 years) thought that urinary incontinence was normal for their age. Hart et al concluded that perimenopausal women may have particular educational needs regarding bladder function and incontinence.

Holst and Wilson’s (1988) study of women aged 18 years and older living in the community found that only 35% of women with regular incontinence (ie two or more episodes per month) had sought medical help. Once again, the most common reason for not seeking help was viewing urinary incontinence as normal or having low expectations of obtaining any benefit from treatment.

Rekers et al (1992) in their study of 1,299 women aged 35 to 79 years living in the Netherlands, found that almost half of the 344 women who had urinary incontinence used protective sanitary towels, yet only 13% considered themselves to be handicapped by their continence problems and only 28% had ever sought medical assistance. Of those with serious incontinence problems, 44% had consulted a doctor. On average, the continence problem had been present for 7.5 years at the time of the study. The main reason (given by 87% of the incontinent women) for not seeking help was that they did not consider the symptoms to be serious enough. Other reasons for under-reporting were fear of surgery (36%), and negative expectations about treatment possibilities (29%).
Fifteen per cent of the incontinent women indicated that they could not or would not want to talk about their problem. Of these women, 40% did not want to discuss the problem, 34% did not know who to approach, and 20% thought that other people could not help them.

Diokno et al (1986) studied 1,955 community living people in Michigan, who were all aged over 60 years. They reported that 38% of the incontinent men and 41% of the incontinent women had told a doctor about their continence problems.

Lara and Nacey (1994), using a self-administered questionnaire, found that although 50% of incontinent women in their New Zealand study wanted help with their urinary incontinence, only 26% had actually sought medical assistance. Many regarded their incontinence as a normal occurrence. This study also found that the failure to seek help had a similar occurrence across ethnic groups, with most women across all groups considering urinary incontinence to be normal. One third (33%) of Pacific Island women in the study, 27% of Maori women, and 19% of European women gave embarrassment as the reason for not seeking medical help. Twelve per cent (12%), 18% and 34% respectively from each group felt that their incontinence was not severe enough to require medical help.

Norton et al (1988) studied 201 successive women aged 16 years to 86 years (mean age 49 years) undergoing initial assessment at two urodynamic clinics in London. The study examined the reasons for delay in seeking treatment. Most of the study subjects had delayed seeking medical advice for more than a year. The reasons given by these women for their delay in seeking medical advice were:

- they hoped that the symptoms would get better on their own;
- they were too embarrassed to discuss the problem with their general practitioner;
- they were afraid of needing an operation; and/or
- they thought the symptoms were normal.

Turan et al’s (1996) study of urinary incontinence in Turkish women of reproductive age found that 85% of the incontinent women had never sought medical help. Of these non-reporters, 90% considered their symptoms were not important enough. Other reasons given for not seeking medical assistance included fear of surgery, financial barriers and being ashamed of their incontinence.

The reasons given by the women in Jolleys (1988) study for not speaking to a doctor about incontinence were:

- the women did not consider their symptoms to be a serious problem;
- they felt their symptoms were too infrequent to warrant treatment;
- they thought their symptoms were a normal female complaint; and/or
- they were too embarrassed to speak to their doctor.
Other reasons given in Jolley’s study for not reporting incontinence included: believing that the symptoms were due to ageing or child birth; they had “not got round” to consulting the doctor; and fear of surgery. Jolley found that the more factors precipitated their incontinence, the more likely patients were to consult a doctor.

Burgio et al (1994) undertook a study by survey of 1,104 community-dwelling ambulatory older adults, aged 65 to 79 years who had self-reported urinary incontinence. The study found that 37.6% of the participants had told their physician about loss of urine. This study also found that reporting behaviour was strongly associated with severity of incontinence (as measured by the frequency and volume of accidents, the extent to which the person’s activities were restricted and mood affected, and the use of protection). Reporting behaviour was also related to type of incontinence, physical disability and the pattern of health care utilization. Younger age, physical disability and the frequency of physical and rectal examinations had significant predictive value, independent of the severity of incontinence.

Mitteness (1987) reported that elderly people viewed incontinence as “not important enough to bother a doctor” and thought that treatment for incontinence was only appropriate for younger people. In terms of social factors, the more close friends the person had with whom they could discuss personal matters, and if they shared health information with friends, the more likely they were to report their continence problems to a doctor. Gender, marital status, income, employment status, educational level and distance from the service provider were not associated with treatment seeking.

Burgio et al (1994) proposed two possible reasons for their finding that health care utilization was a strong independent predictor for reporting continence problems:

1. More contact with health care providers resulting in more opportunities for the provider to ask about specific conditions.
2. Increased contact and familiarity with health care providers making people more comfortable about discussing incontinence.

Burgio et al cited the previous studies of Diokno et al, 1986; Ouslander et al, 1982; Thomas et al, 1980; Holst & Wilson, 1988; and Mitteness, 1987, to note that while urinary incontinence affects approximately 30% of older adults living in the community and over half of those who reside in nursing homes, less than half of these people are evaluated or treated for their incontinence. Furthermore, the previous studies showed that 10% to 70% of people with incontinence had reported this condition to a health care provider, ie reporting their incontinence had not resulted in evaluation or treatment of the condition.

The studies of older adults living in the community found that between 38% and 48% of men and 41% to 56% of women had reported their incontinence to a doctor. Burgio et al concluded that while there does appear to be a relationship between both age and severity of incontinence and the likelihood of reporting, gender does not appear to affect this
decision. Their review of the research identified the following common reasons for not reporting incontinence to a health worker (not in any rank order):

- incontinence was not considered abnormal;
- low expectation of treatment benefits;
- unawareness that treatment was available;
- cost;
- symptoms were too mild or too infrequent to warrant treatment;
- embarrassment;
- hope that it would improve without treatment;
- fear of surgery; and
- patient’s belief that they were too old.

**Under Reporting of Faecal Incontinence**

Prosser and Dobbs (1997) found that only 49% of over 75 year olds who had ever experienced faecal incontinence and only one (13%) of the eight patients experiencing daily faecal incontinence or their carer had discussed the problem with a health professional. Those who had reported their continence problems had done so to a GP in 82% of cases, a nurse in 30% of cases and another professional in 19% of cases. (Note that these categories were not mutually exclusive.)

Gordon et al’s (1999) study of urogynaecological clinic patients with faecal incontinence found that although 29% of the study population reported faecal incontinence when interviewed and asked directly, only 17% of these patients had ever consulted a doctor for this problem and only 2% complained of faecal incontinence during clinical assessment, prior to the survey being administered.

“The symptoms (of faecal incontinence) may be hidden by women who either assume these symptoms to be part of their lot following childbirth or are not willing to admit to the problem.” (Walsh et al, 1996, p219)

Compounding the issue of embarrassment as a major reason for under-reporting of faecal incontinence is a lack of awareness, amongst consumers and health practitioners, of the potential benefits of surgical repair, where the incontinence is due to anal sphincter damage during childbirth (Walsh et al, 1996).

In MacArthur et al’s (1997) study, although only five of the 36 women with faecal incontinence had consulted a doctor about this problem, a further four women had consulted about other bowel symptoms. In this study, the reasons given by the women for not consulting a doctor included:

- the women thought that the symptoms would eventually improve;
- they felt they hadn’t had the symptoms long enough to warrant going to the doctor;
they perceived that the problem wasn’t severe enough or that they could cope with it;
they felt too embarrassed;
they considered it was all part of having a baby; and/or
they didn’t think the doctor could do anything about the problem.

“Nonconsultation probably accounts for the previous lack of recognition by the medical profession of this problem as an immediate consequence of childbirth. When asked why they had not consulted a doctor, women gave reasons which did not accord with their own reports of symptom duration or frequency. Such responses are more likely to represent post hoc rationalizations following a decision not to consult, probably influenced by the sensitivity attached to these types of symptoms.” (MacArthur et al, 1997, p50)

Leigh and Turnberg (1982) studied 76 consecutive patients with diarrhoea seen in a gastrointestinal clinic. Fifty-one per cent (51%) of these patients admitted to faecal incontinence when questioned carefully and directly about this, but fewer than half of these volunteered this information spontaneously. The researchers concluded that faecal incontinence may be a “frequently unvoiced symptom” in patients with diarrhoea. They suggested the reluctance to admit the problem was due to patient embarrassment and/or the reluctance of health professionals to embarrass patients by asking about it. Leigh and Turnberg noted that about half of their patients were referred to the clinic because of diarrhoea when their main problem was incontinence.

3.3 Role of Health Practitioners in Patient Reporting of Incontinence

From their qualitative study of 21 GPs in Ireland, Grealish and O’Dowd (1998) concluded that: “many GPs avoid dealing with the problem of urinary incontinence in women.” The authors also noted that: “Male GPs in particular were reluctant to carry out gynaecological examinations, and few GPs expressed enthusiasm for teaching pelvic floor exercises or bladder drills.” (p 975). The most common problem reported by GPs was lack of time to adequately assess and manage the incontinent patient. A further finding was that the services of continence nurses were rarely used by GPs and many GPs were not aware of these services.

Grealish and O’Dowd reported that despite the financial and social costs of incontinence, up to two thirds of women with moderate or severe incontinence were not known to their GPs (citing the studies of Thomas et al, 1988; Lagro-Janssen et al, 1990; and O’Brien et al, 1991).

In another study involving GPs in Ireland, Prosser and Dobbs (1997) analysed data for 527 patients aged over 75 years. They found that 44% of these patients reported (through a questionnaire) that they had experienced urinary incontinence and 9% reported having experienced faecal incontinence. The GPs reported that they had full knowledge of continence status in only 33% of their patients. In 30% of cases the GPs had partial knowledge and in 37% of cases they had no prior knowledge of the patient’s
incontinence. Prosser and Dobbs concluded that GPs should have a “high index of suspicion for incontinence in persons aged over 75” and recommended thorough history taking, physical examination and therapeutic options.

Telephone surveys of urologists, gynaecologists and primary care physicians in Massachusetts and Oklahoma found that only 21% of the physicians in Massachusetts had asked at least three quarters of their elderly patients about urinary incontinence during the previous month, and only 23% of the physicians in Oklahoma reported always asking new patients about urinary incontinence (Branch et al, 1995). The authors concluded that although clinical practice guidelines for urinary incontinence had been disseminated, many of the physicians did not know how to diagnose or treat urinary incontinence. The Massachusetts survey identified the most common reasons given by physicians for not asking patients about urinary incontinence were lack of time (36%), lack of available and effective treatments (28%) and patient embarrassment (26%).

Wellings (1988) referred to a study by Starer (1985) which found that although nurses documented incontinence in 62.4% of 511 residents in a New York City nursing home, the physicians had only identified this problem in 10% of the same population. Wellings suggested this indicated either a lack of rigour in assessment or ignoring the problem when it existed. Wellings also suggested that: “Incontinence is likely to be promoted in the elderly by general acceptance of the inevitability of the condition. Lack of professional education and poor community awareness are at the heart of the problem.” (p.8)

Chutka et al (1996) suggested that the complexity of urinary incontinence deters many doctors from undertaking assessment and treatment with the result that many patients are not asked about incontinence and the condition goes untreated and often is considered to be a natural consequence of ageing.

Mitteness (1987) reported that the response from the physician to an elderly person reporting continence problems may be “less than vigorous” and described a prevailing attitude among health professionals that urinary incontinence is inevitable in old age and untreatable. Nearly half of the incontinent elderly people in Mitteness’ study who had consulted a physician reported that the response was dismissive or their complaint of incontinence symptoms had been ignored. Mitteness concluded that:

“Elderly people resign themselves to having bladder disturbances because they feel such problems are inevitable and intractable, and because no health professional has ever told them otherwise.” (p.188)
O’Brien (1998) emphasized the importance of asking patients about faecal incontinence if this is suspected:

“Patients tend to hide the problem from their doctor as they hide themselves from the public. Instead, they may complain of diarrhoea, urgency or urinary symptoms. If you do not actively seek the information in a supportive way, more than 50% of patients will not volunteer it. Find out if there is loss of solid faeces, or liquid or gas. Ask whether the problem occurs every day, most days, once a week or only occasionally.” (p.110)

3.4 The Arguments for Increasing Reporting of Continence Problems

There are sound arguments for increasing the level of reporting, identification, assessment and treatment of incontinence of both urinary and faecal types for a range of age groups, with resultant social and economic benefits for patients, carers and the health, aged care and community service systems.

Social Impacts of Untreated Continence Problems

Millard (1998) referred to: “a large reservoir of untreated incontinence people in the community who never seek treatment or are perhaps too frightened or embarrassed to ask for help.” Millard added:

“Not uncommonly, individuals attend for help only after many years of misery, having been under the misapprehension that nothing could be done for them. This must represent a significant failure of medical education in the community and is a considerable cause of suffering for many thousands of individuals.” (p.98)

Fonda et al (1995) concluded that:

“Given the psychological impact of incontinence, it is disappointing that so few people seek professional help for this condition when so much can be done to improve the condition as well as quality of life.” (p. 285)

Fonda et al (1995) went on to recommend that:

“Destigmatisation of urinary incontinence clearly is important and there is a need to develop national continence awareness programmes that will encourage patients to come forward and seek help.” (p.285)

Shapiro and Setterlund (2000) described the worry that women with urinary incontinence have about maintaining control of their body while socializing and the devastating effects that urinary incontinence can have on independence and ability to socialize and maintain relationships with families and friends. Thirty four per cent (34%) of the women in their study reported feeling depressed because of their urine loss and more than 50% said they
worried about being embarrassed or humiliated. Over 40% of the study’s respondents worried about other people smelling the odour of urine on them.

Samuelsson et al (1997) found that self-assessed health, sleep, fitness and satisfaction with work situation decreased significantly with increased frequency of incontinence in a sample of 491 women aged 20 to 59 years, although well-being was not correlated to type of incontinence. All women with incontinence problems in this study were offered treatment. Of these women, 36% were interested in treatment and 24% actually started treatment. The researchers found that the wish for treatment correlated to the severity of problems. Other variables of type of leakage, sleep, and other indicators of well-being were not significantly different between those desiring treatment and those not desiring treatment. Of the 35 women who actually commenced treatment, 28 completed treatment.

Lara and Nacey (1994) described the psychological effects of incontinence on self esteem and the need to make life style and social changes to avoid embarrassing situations. They suggested a need for increased awareness of the nature of incontinence, what services are available and how to access these. These authors recommended “improved public education, preferably community based, so that all socioeconomic and ethnic groups can be properly catered for.” (p.376)

The social effects of faecal incontinence can be particularly devastating.

“Even when it occurs only episodically, anal incontinence has catastrophic consequences on self-confidence, personal image, and ability to integrate socially and in employment. Ultimately, faecal incontinence is often associated with nursing home admission.” (Nelson et al, 1995, p.559)

Mitteness (1988) reported the strategies used by elderly incontinent people living in the community. These strategies included: substantial reorganization of daily activities so that any accidents take place in private; altering diet; adjusting the times at which diuretic medication is taken; increasing the frequency of toilet visits, particularly when traveling; frequent laundering of both soiled and unsoiled clothing to alleviate fears of odour; developing a “cognitive map” of toilet locations in public places and destinations; and non-disclosure of continence problems to health professionals or others. Mitteness and Barker (1995) described the linkage of incontinence with incompetence and the strategies that elderly people are forced to adopt so as not to compromise their competence in the eyes of others.

**Successful Treatment Outcomes**

There are a number of recent studies demonstrating the effectiveness of treatment, including non-invasive treatment, for incontinence. Unfortunately, awareness of these positive treatment outcomes is limited amongst many consumers and health practitioners.
Mitteness and Barker (1995) described the anomaly between the consensus of research literature that urinary incontinence in the elderly is treatable and frequently reversible and the perceptions of the elderly and their health care providers that incontinence is inevitable, irreversible, and a normal part of growing old.

Prosser and Dobbs (1997) noted that even in complex cases, the cause of incontinence in older people can usually be determined non-invasively and that drug therapy, pelvic floor exercises and behavioural programmes have been demonstrated to be useful therapeutic options for this age group.

Hilton and Stanton (1981) found that 60% of invasive investigative procedures carried out on elderly women with urinary incontinence could be eliminated with minimal loss of diagnostic accuracy using an algorithmic method of assessment.

The success of non-invasive treatments has been well described in the research literature. Grealish and O’Dowd (1998) referred to Jolley’s (1989) report that 41% of women with stress incontinence were totally cured after 12 weeks of pelvic floor exercises explained to them by a GP and 88% had improved. Wymen et al (1997) undertook a randomized controlled six week trial of bladder training for 123 older women with urinary incontinence. Using clinical and quality of life measures, including the Incontinence Impact Questionnaire, they found that regardless of urodynamic diagnosis, bladder training is effective in improving the quality of life of incontinent women.

Chutka et al (1996) suggested that older adults need to be reassured that for most patients, diagnosis and treatment of urinary incontinence is inexpensive, non-invasive and successful.

About one quarter of the incontinent women in Samuelsson et al’s (1997) study started treatment when offered and 80% of those who completed the treatment program were subjectively improved.

The use of nurses with some degree of continence awareness training has also been shown to be effective. For example, a study by O’Brien et al in 1991 demonstrated that a nurse given limited training could effectively manage people with regular incontinence. The subjects in this study received four sessions of pelvic floor exercises and bladder retraining supervised by a non-specialist nurse who had taken a three week course on assessing and treating uncomplicated incontinence. The study demonstrated outcomes for women with stress incontinence as successful as those achieved by a physiotherapist. Over half of the women with urge incontinence also improved following treatment by the nurse.

Schofield and Wheaton (1992) found that support and education in a small group environment, facilitated by a Continence Nurse Advisor and a social worker, assisted in changing attitudes and promoting compliance with individual programs, including dietary changes, pelvic floor exercise routines, toileting programs, medication and meditation.
Successful treatment outcomes have been demonstrated for incontinent residents of aged care facilities. Tobin and Brocklehurst (1986) found faecal incontinence occurring at least once weekly in 10.3% of the residents in 30 residential homes for the elderly in England. Although incontinence had been present for over a year in 73% of these residents, only 4% had been referred to their general practitioner. This study achieved full compliance with the recommended treatment in 66% of the cases, and 87% of these were cured, compared with 32% of a control group during the same period. Tobin and Brocklehurst concluded that “in the great majority of cases faecal incontinence in old people is both curable and preventable.” (p41)

3.5 Strategies for Increasing the Reporting of Incontinence

Several research studies have suggested strategies for increasing the reporting of incontinence. Repeated themes emerging from the research have been the need for public education about incontinence and increased attention by health practitioners to continence problems.

Norton et al (1988) recommended:
- Informing women that help is available for continence problems and that many symptoms can be alleviated, if not eradicated without surgery.
- Providing people with accurate and current information to reduce the stigma associated with incontinence and to open the lines of communication with their health care providers.
- Encouraging general practitioners to raise the subject of continence problems with their patients.
- Encouraging health workers to be sensitive to the emotional and social distress associated with continence problems.

Holst & Wilson (1988) recommended improved education, especially among younger women, that incontinence is treatable and there are a range of treatment options (including non-surgical treatment) available. Turan et al (1996) also suggested more public education and greater attention to urinary problems, including incontinence, by physicians. The two key messages suggested by these authors for a public education campaign were that help is available and that treatment does not necessarily require surgery.

Burgio et al offered the following suggestions for increasing reporting of incontinence in the older population:
- doctors and nurses should inquire about incontinence during routine health care visits;
- public education and awareness about incontinence should be increased, particularly for those who use health services less frequently; and
- the myths and widespread beliefs that urinary incontinence is a natural and inevitable consequence of ageing and of childbearing and that incontinence is untreatable should be corrected through public education.
Following their consultations with older women in Queensland and New South Wales, Shapiro and Setterlund (2000) recommended a public education campaign “to raise community awareness of the nature and impact of urinary incontinence and to break down taboos against discussion of both urinary and faecal incontinence” (p.5) These authors also recommended training programs for medical practitioners and other health and community workers, with an emphasis on “non-ageist, non-sexist, cross cultural practice.” (p.5)

3.6 Summary
The proportion of people who have urinary incontinence but do not report it, is likely to be at least 50% and it may be higher than 60%, depending on factors such as age group, type and severity of incontinence. The under-reporting of faecal incontinence is even higher, with studies indicating that more than 80% of people with this problem have not reported it to a doctor.

The major reasons for under-reporting identified in the research literature include:

- people assuming that incontinence is normal for their gender and age group;
- not knowing that effective treatment is available;
- embarrassment;
- thinking that their problem is not severe enough to warrant medical attention;
- fear of surgery; and
- hoping that the symptoms will improve on their own.

Research studies show that in most cases continence problems (urinary and faecal) can be successfully treated, often without surgery or invasive investigations.

Researchers’ main suggestions for increasing reporting behaviour are:

- encouraging health workers (doctors and nurses) to specifically but sensitively inquire about continence problems during routine health checks; and
- improving public education and awareness to dispel the common myths regarding incontinence ie that incontinence is an inevitable result of ageing and childbirth and that it cannot be treated.
4.0 Results of Stakeholder Consultations: Reasons for Under-Reporting of Incontinence

4.1 Introduction

The terms of reference for this project required the consulting team to:

- gather qualitative and quantitative information on reasons for under-reporting of both urinary and faecal incontinence; and
- assess what the cultural, social and physical barriers are to seeking treatment.

In addition to reviewing the results of research studies undertaken in this area (as reported in Section 3), our project methodology involved a range of consultation activities with key consumer, carer, community health and specialist continence practitioner representatives. The consultation methods used were focus groups, interviews, written questionnaires and written submissions. Please refer to Section 2.2 of this report for full details of the consultation activities.

The focus groups and interviews, in particular, enabled individual consumers and health workers to describe their personal experiences in respect of reporting continence problems and access to information, services and treatment. The questionnaire responses provided further descriptive information and also quantifiable data regarding the reasons for under-reporting.

This section of the report describes the findings from our consultations, specifically:

- the significance of continence problems and reluctance to report these problems encountered by health and aged care workers;
- the social and cultural barriers to reporting continence problems identified by consumers, carers and service providers;
- the barriers of knowledge and information that may hinder the recognition of a need to report continence problems;
- other reasons for under-reporting described by stakeholders in our consultations;
- the role of health practitioners in the reporting process ranging from encouraging patients to discuss these problems, through to providing appropriate treatment and referral;
- issues for Aboriginal and Torres Strait Islander peoples in reporting continence problems to a health worker; and
- issues for ethnic communities.

Much of the material presented in this section is generated directly from the comments of stakeholders. We do not suggest that these comments are representative of all members of the Australian community or of all members of a particular cultural or linguistic group. One of the most important findings from our consultations is that while there are common
themes, issues and reasons for under-reporting of continence problems, each person is individual in their needs and willingness to discuss these problems and a sensitive, individualized approach is needed from the health practitioners and community workers providing services in this area.

4.2 Significance of Continence Problems and Reluctance to Report

Incontinence was considered by most of the health and aged care workers we surveyed to be a significant issue for their clients. Health and community workers and members of Aged Care Assessment Teams responding to questionnaires were asked how significant the issue of incontinence was for their client group. Of those responding to this question:

- 97% (64) of the health and community workers (mainly GPs and community nurses); and
- 87% (93) of the ACAT members

rated the issue of incontinence as very significant or significant for their client group.

Most of the respondents described their clients with continence problems as being post-menopausal or elderly women.

Despite the significance of continence problems, it would appear that the many of these clients do not seek or receive assistance. ACAT members were asked to estimate the proportion of their clients with continence problems who have ever sought or received a detailed assessment of their continence problems:

- 28% (30) of the respondents estimated that this proportion was less than 10%;
- 27% (29) estimated 10 – 25%; and
- 15% (16) estimated 26 – 50%.

The majority of health and aged care workers had encountered reluctance by clients to disclose their incontinence. When asked by questionnaire if they had experienced any reluctance by clients to disclose their continence problems,

- 68% (36) of health and community workers;
- 80% (12) of the specialist continence practitioners; and
- 87% (93) of the ACAT members

responded yes.

“Some clients have been managing their own incontinence without revealing their problem to their GP. – only diagnosed when full assessment attended on admission to Community Nursing.” (Health and Community Worker questionnaire respondent)

“You might go and visit a client for another problem but inevitably find out in the assessment they have continence problems.” (Health and Community Worker questionnaire respondent)
4.3 Social and Cultural Barriers

Stakeholders described a number of key social and cultural barriers to the reporting of continence problems.

4.3.1 Embarrassment

Embarrassment was identified as a major reason for people failing to report or seek assistance with their continence problems across all stakeholder groups and consultation methodologies. Embarrassment was specifically cited as a barrier in reporting of continence problems by:

- eight of the nine focus groups conducted for this project;
- 42% (9) of the respondents to the questionnaire for peak bodies and advocacy groups;
- 60% (9) of the respondents to the questionnaire for specialist continence practitioners;
- 45% (30) of the respondents to the questionnaire for health and community workers; and
- 39% (41) of the respondents to the questionnaire for members of Aged Care Assessment Teams.

Many of those consulted described a general reluctance to discuss and disclose continence problems due to the shame and ‘social taboo’ associated with incontinence. Consumers and service providers suggested that the issues of embarrassment and shame were common to all cultural groups.

“We are socialized from an early age about the connotations of incontinence.” (Focus group participant)

“From my experience many clients are often very embarrassed by continence problems and have difficulty disclosing this to a stranger, or down play how significant the continence problem is.” (Aged Care Assessment Team questionnaire respondent)

“People are often reluctant to discuss continence issues. Many women find the issue embarrassing and men often feel like this problem is due to ‘lack of strength, manliness’.” (Aged Care Assessment Team questionnaire respondent)

“People born and bred here (a country town) are more timid about asking about these things. They are not willing to open up to others. Intimate talk is a definite no-no.” (Consumer participating in telephone interview)

“Incontinence is not just a social issue. It strikes at the very core of an individual’s sense of dignity and feelings of self worth. That is why it is under-reported and why the full extent of the financial burden is often hidden.” (Peak Body/Advocacy Group questionnaire respondent)
“From a carer’s perspective, various factors contribute to under-reporting. These include:

1. **Stigma associated with incontinence and lack of general discussion/acceptance of the issue as a common problem in the community.**

2. **Embarrassment and shame felt about the problem, which creates a reluctance to raise and discuss the problem with others. The care-recipient may feel this way, so not disclose difficulties to the carer or the carer his/herself may experience this embarrassment.**

3. **Incontinence concerns an intimate area of hygiene and carries powerful messages from childhood about one’s adequacy, independence and maturity. Both carers and care-recipients can struggle with conflicting emotions and attitudes in dealing with the issue. Faecal incontinence in particular has stronger taboos and reactions attached.” (Submission from Carers’ Association of Victoria)

*Carers NSW* conducted their own small survey.

“In conversation with half a dozen people caring for relatives with a continence problem, the embarrassing nature of continence problems was mentioned almost every time. Thus, we believe that the ‘embarrassment factor’ is a psychological barrier to people raising continence issues.”

The embarrassment experienced by people with continence problems may continue through treatment even after the hurdle of initial disclosure has been cleared.

“There is a series of humiliations in obtaining treatment. Pelvic floor treatment can be very embarrassing . . . There is a series of steps and every step is shameful and embarrassing. The circle of people who know about your problem gets wider and wider, from the GP to the physio, physio’s receptionist, pharmacist, etc. As you work through each step, it becomes more and more tempting to just give up.” (Consumer interview participant)

It may require a significant incontinence accident or an important social event to persuade a person with incontinence to seek assistance.

“Some people wait until the problem becomes major and they can no longer hide or manage their incontinence. Sometimes a special social occasion such as a son or daughter’s wedding may prompt this.” (Focus group participant)

One focus group noted that advertising for continence products is usually directed at females and so incontinence is viewed by the general community as ‘a women’s problem’. The group suggested that this perception could further heighten
embarrassment for men with continence problems. Reluctance by men to use continence pads (‘women’s things’) is already experienced by continence workers.

Several respondents noted a greater reluctance to report faecal incontinence as opposed to urinary incontinence.

“Women often do not disclose faecal incontinence to their doctors but will complain of urinary incontinence. When asked specifically, they will disclose.” (Specialist Continence Practitioner questionnaire respondent)

**4.3.2 Other Fears**

Several members of Aged Care Assessment Teams responding to our questionnaire described a reluctance by older people to disclose incontinence “for fear of being placed in residential care” or “fear of being seen to be not managing and therefore a fear of having to leave home.”

One consumer focus group participant said that a lot of aged care hostels will decline potential residents if they have continence problems.

“Incontinence is seen as being on your last legs” (Consumer focus group participant)

“Residents in the hostel are reluctant to disclose incontinence problems. Staff find out by increase in change of clothing or they find wet clothing hidden.” (Health and Community Worker questionnaire respondent)

One geriatrician estimated that 30% to 40% of his/her clients with continence problems don’t admit they have incontinence and that these clients were: “Too embarrassed or believe that it is normal and/or being unaware of any treatment/management options.”

Privacy was also identified as a concern with some people reluctant to disclose incontinence during ACAT and other formal assessment processes as they fear that information about their continence problems will be entered on government forms and make its way onto databases.

Amongst younger age groups, other fears were described, such as fear that incontinence symptoms could be associated with cancer (e.g. a bladder cancer or for men, prostate cancer), fear of surgery and fear of being examined.

One service provider pointed out that some continence problems are related to sexual function and that this is rarely disclosed. One provider commented that men are more inclined to associate incontinence with sexual activity. Another suggested that continence services should be better linked with services for sexual dysfunction. Indeed, a number of the male consumers who participated in confidential telephone interviews for this project were more concerned with problems of sexual dysfunction than their
incontinence. Incontinence occurring during sexual activity and orgasm was also reported to be a problem for some people of both genders.

A further suggestion was that all men over 50 years of age should be encouraged to have a general medical assessment including prostate and continence screening.

4.3.3 The Effect of Gender

There were conflicting accounts as to whether males or females were more reluctant to disclose continence problems. Several respondents described reluctance by older males to admit to continence problems and there appeared to be a general view that the social and cultural barriers to reporting problems were stronger in the older populations and in the male gender.

“Inability to control one’s bladder or bowels is a social taboo, more so for the elderly male population in the community.” (Peak Body/Advocacy Group questionnaire respondent)

“Elderly women are embarrassed to talk.” (Health and Community Worker questionnaire respondent)

“Most women feel able to comment on this issue if asked. Some offer information spontaneously, especially in the setting of a Pap smear or HRT (hormone replacement therapy) discussion.” (Health and Community Worker questionnaire respondent)

“Older people don’t talk about ‘that sort of thing’. They think they are the only one with the problem, despite extensive publicity to the contrary.” (Health and Community Worker questionnaire respondent)

“Women tend to be quite accepting eg ‘I lose a bit of water when I cough’ whereas men tend to deny, even when it is apparent, eg stained or wet clothes.” (Aged Care Assessment Team questionnaire respondent)

“Possibly men more than women have difficulty acknowledging they have a problem. Their wives will often indicate to me. If they do accept their problem – the men in particular need persuasion to allow to refer to continence advisor. They don’t seem to believe that they can be helped.” (Aged Care Assessment Team questionnaire respondent)

“Women are much more likely to report incontinence and seek treatment.” (Urologist participating in telephone interview)

“For men, incontinence is a highly embarrassing problem. There is the link to ‘being a man’. Most men won’t get help until it’s beyond self management. They may be more likely to seek help if the onset is sudden.” (Service provider focus group participants)
In respect of carers coping with continence problems, one focus group commented that female carers were more likely to ask for help than male carers and it was suggested that male carers were more reluctant to change continence pads etc and might resort to residential placement once incontinence becomes a problem.

### 4.3.4 Acceptance of the Problem

Another major barrier to reporting of continence problems was a general acceptance or belief amongst people with continence problems (particularly women) that incontinence is ‘a normal part of ageing’ and to be expected as a consequence of childbearing. In some cases it was suggested that these beliefs were reinforced by GPs and by advertising campaigns for some continence products.

“Often women believe it is ‘just a part of getting older’ – ‘that’s what happens when you have children’ etc. Often incontinence has been present for a long time and is accepted.” (Aged Care Assessment Team questionnaire respondent)

“They feel it is a part of ageing, no need to complain – nothing can be done.” (Health and Community Worker questionnaire respondent)

“People believe it is ‘natural’ to have incontinence after childbirth and when aged.”

One focus group suggested that there may be higher acceptance of incontinence in certain age groups, such as menopausal women accepting that stress incontinence when sneezing is normal.

“Women just stop going to aerobics class.” (Focus group participant)

For some people and age groups, other issues and responsibilities may also take precedence over their own needs and continence problems.

“People are too busy – particularly women raising children, and caring for others. Their needs often wait for a decade or so.” (Specialist Continence Practitioner questionnaire respondent)

The tendency for women to cope with urinary incontinence in similar way to menstruation was mentioned in one focus group: “Many women move straight from a sanitary pad to a continence pad”.

“I keep a packet of sanitary napkins in the drawer and use these for travel.” (Woman participating in a telephone interview)

### 4.3.5 Denial

Denial of the problem was another barrier identified in consultations. Several health and aged care workers noted that the carer or spouse (particularly wives) was often the one who reported the continence problem.
“People go in and out of denial – they test what they can tell you. The information they tell you can change over time. You have to give people time to talk about their continence problems in their own way.” (Participant in a service provider focus group)

“They can only be fully assessed if they concede to their problems... if they are hiding their incontinence, carers must earn their trust in order to help them appropriately. Some refuse help in the belief that no-one knows they are incontinent.” (Specialist Continence Practitioner questionnaire respondent)

“Personal resistance – they feel they are managing and don’t want to change their lifestyle. Doctor has told them their problem cannot be fixed or cannot be fixed without an operation.” (Aged Care Assessment Team questionnaire respondent)

A carers’ organisation identified a number of reasons why care recipients might deny their continence problems.

“The care-recipient may themselves deny or try to minimize the problems they are experiencing, because of:

- what this means for their self esteem and sense of self;
- cognitive impairment as with dementia;
- what they perceive may be the consequences of revealing the problem eg placement in residential care; their home ‘invaded’ by strangers such as nurses, personal care or home help workers.” (Submission from the Carers Association of Victoria)

4.3.6 Reluctance to Approach a GP

Thinking that their continence problem was not sufficiently important to take up their GP’s time was also a reason given for not reporting the problem.

“Most clients self refer (to a continence nurse) but most have had their problem for ‘years’. A few of these had discussed with their GP but most said they ‘didn’t want to bother’ the doctor with continence problems.” (Specialist Continence Practitioner questionnaire respondent)

“Some clients have expressed the fact that their GPs are ‘so busy’ they did not want to bother them with what the clients believe is not an urgent or critical problem for the GPs.” (Specialist Continence Practitioner questionnaire respondent)

Focus group participants noted that incontinence is a ‘difficult topic to talk about with GPs’.
“People don’t like talking about things like that with their doctor.”
(Consumer focus group participant)

“Can you sidetrack the doctor (GP) and go straight to a specialist?”
(Consumer focus group participant)

“On some occasions, clients for wound care etc have not disclosed information re continence problem, but after a few visits have discussed issues. On these occasions felt embarrassed talking about it but felt they could talk to nurse rather than their GP.”
(Health and Community Worker questionnaire respondent)

Several individuals and groups we consulted noted the reluctance of females to tell male GPs about their continence problems, although as one participant pointed out, embarrassment is still an issue even when the patient is consulting a health worker of the same sex.

It was suggested that females may be reluctant to discuss their continence problems with a male health professional (usually their GP) and conversely, males with continence problems may be reluctant to discuss continence issues with a female health worker. This presents something of a gender dilemma for the majority of GPs who are male and the majority of continence nurses who are female.

“Reluctance on part of client to discuss this problem especially with health professional of different sex.”
(Aged Care Assessment Team questionnaire respondent)

“Men often don’t like admitting to this problem, especially if a female is asking the questions.”
(Aged Care Assessment Team questionnaire respondent)

“Reluctance to discuss this with a stranger – particularly if client is elderly female and assessor is male.”
(Aged Care Assessment Team questionnaire respondent)

“One service provider reported that some female clients had withdrawn from their referral when they found out that the continence nurse was male.

“Many people I see have come to see me serendipitously or tortuously! ie I see them as a social or community nursing referral and find out about the continence problem at my assessment.”
(Specialist Continence Practitioner questionnaire respondent)
4.4 **Knowledge and Information Barriers**

A range of knowledge and information barriers to reporting incontinence were identified by those participating in research consultations.

4.4.1 **Understanding of Incontinence**

Many respondents to the questionnaires suggested that a lack of knowledge and understanding about what continence is, what causes it, and/or what can be done to help is a major reason for under-reporting of continence problems.

> “Some older people are unaware that it is not normal to be incontinent and don’t realize it can be helped.” (Specialist Continence Practitioner questionnaire respondent)

> “People think incontinence is just part of growing old and a consequence of childbirth and that they just have to put up with it.” (Focus group participant)

> “Personal recognition/awareness that their problem actually is a problem that something can be done about. Many accept ‘leaks’ as ‘part of life’.” (Specialist Continence Practitioner questionnaire respondent)

One peak body suggested that people perceive incontinence as total loss of bladder and/or bowel control and don’t realize that leakage at the ‘less serious end of the scale’ is also incontinence. People with leakage problems may not identify themselves as incontinent and may not respond to information campaigns, advertising or other strategies where the term *incontinence* is used.

A further concern was the lack of knowledge about the continence services that are available.

> “... a major barrier to accessing continence information and services for all groups of carers is a lack of knowledge about what is available. Unless a health professional, such as a GP, geriatrician or an information service like our own has informed the carer of what is available, they are unlikely to stumble across such information.” (Peak Body/Advocacy Group questionnaire respondent)

4.4.2 **Awareness of Services and Treatment Options**

The lack of knowledge among consumers, carers and even health professionals about the continence service and products available was highlighted by most focus group participants and questionnaire respondents.

> “People assume that there is no medical treatment and that nothing can be done.” (Focus group participant)
Others described a lack of awareness of the prevalence of incontinence and people thinking they are the only one with this problem.

“Main barrier is lack of information. Clients are not aware that aids are available through the government and also some clients are not aware that products are available for incontinence.” (Health and Community Worker questionnaire respondent)

Another factor was self management of the problem and a reluctance to seek help or intervention when the person was able to contain their incontinence through the use of pads.

One concern raised by several focus group participants was the tendency to focus on containment of the incontinence, for example by the use of pads, rather than on treatment and rehabilitation options. It was suggested that poor awareness and understanding of the treatment options available resulted in the assumption that pads and other barriers were the only solution.

“Lack of knowledge of continence treatment options amongst the general public reinforces the individual’s expectations that there is nothing that can be done.” (Focus group participant)

There was also a concern that many people believe that the only treatment option is surgical and that there is a lack of information and awareness about non-surgical treatments.

One service provider suggested that people not only don’t know that help is available, they also don’t know how to ask for information.

4.5 Other Reasons for Under Reporting

A number of access and availability issues such as availability of services (particularly in rural and remote communities) transport needs and cost of services and equipment were highlighted by questionnaire respondents and focus group participants. Fear of the cost and expense of continence services was listed by one focus group as a reason for under reporting by those who are not privately insured. These access issues are explored further in Section 5.0.

The relative priority and importance of incontinence for the individual, particularly where the person has multiple health and other problems can also be a reason for not reporting.

One focus group suggested that a hospital environment with its lack of privacy is far from conducive to disclosure of continence problems. Specific concerns regarding privacy and confidentiality were also raised in respect of small rural communities and in cases where inappropriate interpreters were used.
“My current doctor is not aware of my continence problems. It’s a matter of social shyness as I know him outside in a social sense.”
(Consumer from a country town participating in a telephone interview)

Difficulties for people with dementia and other cognitive impairments in accepting and recognizing their continence problems were reported.

4.6 The Role of Health Practitioners

The important role of General Practitioners (GPs) and other primary health care workers, such as community nurses, community health centre staff, and domiciliary care/home help workers in identifying continence problems and assisting people to seek appropriate advice, assessment and treatment was reinforced by all focus groups and respondents to all of the questionnaires.

The general reluctance to disclose continence problems, described in 4.1 above, requires a skilful and considered approach to raising the issue by health practitioners. The need for a good rapport and a trusting relationship between the health practitioner and patient/client was emphasized.

“If the health professional is comfortable talking about incontinence, the patient will disclose more. Health professionals need empathy, listening and communication skills.” (Focus group participant)

“Patients need time to feel secure with whom they will disclose this information.” (Specialist Continence Practitioner questionnaire respondent)

Several respondents to the Health and Community Workers questionnaire and the questionnaire for members of Aged Care Assessment Teams noted that they had to specifically ask their patients/clients about continence problems and that clients would not raise this issue without such a direct question. The importance of GPs and other health professionals initiating discussion with their patients about continence problems was stressed by several respondents.

“GPs could be more proactive when seeing their patients. They often don’t ask and people are too embarrassed to say anything.” (Aged Care Assessment Team questionnaire respondent)

“Incontinence continues to be something of a ‘no-go’ area which leads to the question not being asked or the problem not being identified as ‘a problem’. On occasions, someone who has complained of reduced bladder control is tested for an infection with a negative result, yet no further options are provided. Greater education of health professionals, especially GPs, and public awareness programs targeted at the risk groups, for example in the Aged Pensioner news, may be helpful.” (Aged Care Assessment Team questionnaire respondent)
“It would help if doctors routinely asked patients about continence problems (as they do for checking blood pressure, Pap smears and so on).” (Focus group participant)

This role was not just seen as the domain of primary health care workers but also as an important point for specialists.

“Men with prostate surgery-related incontinence don’t see the link between prostate and continence or the role of the urologist in treating incontinence. There may be a similar issue for women not wanting to bother the gynaecologist with something as ‘minor’ as incontinence. They may accept incontinence as an inevitable side effect. Specialists may not be raising the issue with patients.” (Focus group participants)

One service provider focus group suggested combining breast screening, Pap smears and continence assessment into the one women’s health program, with these checks routinely combined in one visit to the GP or health clinic. A similar men’s health routine assessment could also be designed.

4.6.1 Practitioner’s Knowledge and Understanding of Continence Issues

The importance of consumers and carers receiving a positive response from health professionals when they actually do pluck up the courage to raise the topic of continence problems, was emphasised by several consultation participants. General practitioners and community nurses must therefore have an adequate level of knowledge regarding the assessment, management and treatment of incontinence and at the very least, know where to refer patients for more specialized investigation.

“One major factor seems to be the past experience of the client receiving no help or advice when raising the issues with their GP – so they say ‘why bother to ask anyone again’.” (Health and Community Worker questionnaire respondent)

“If the patient has previously been dismissed by another health professional as not needing help, or it is their age, they are reluctant to keep raising it as an issue.” (Specialist Continence Practitioner questionnaire respondent)

“Older women are more timid about seeking help. GPs only tell them to get pads.” (Consumer participating in telephone interview)

“I have reported it to my GP but he said ‘that happens with prostate problems’. (Consumer participating in telephone interview)

“They don’t get an effective response when they do report it!” (Focus group participant)
“Many GPs verbally explain pelvic floor exercises but not enough information is given or individual assessment made for strength and endurance or even if it is being done properly.” (Specialist Continence Practitioner questionnaire respondent)

Participants in one of the service provider focus groups pointed to insufficient content regarding incontinence in health (including medical), allied health and nursing training curricula.

One participant in a service provider focus group was concerned about the replacement of nurses and other qualified health workers with community workers “who may not identify continence as an issue or have the knowledge to manage this or direct the person to appropriate services.” In another group it was suggested that domiciliary care workers and personal care support workers may in fact be the ones most likely (due to their close and extended contact) to identify that a person has continence problems. Training and information for these workers may therefore be particularly important. (Refer to Section 7.0 for further discussion of training needs)

### 4.6.2 Identifying and Assessing Continence Problems

When asked who provides continence assessments for their clients, members of Aged Care Assessment Teams responded as shown in the table below.

<table>
<thead>
<tr>
<th>Who generally provides continence assessments for ACAT clients</th>
<th>No of ACAT Questionnaire Respondents n=107</th>
<th>% of ACAT Questionnaire Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continence Nurse</td>
<td>93</td>
<td>87%</td>
</tr>
<tr>
<td>Community Nurse</td>
<td>47</td>
<td>44%</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>22</td>
<td>21%</td>
</tr>
<tr>
<td>Geriatrician</td>
<td>19</td>
<td>18%</td>
</tr>
<tr>
<td>Urologist</td>
<td>19</td>
<td>18%</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>9</td>
<td>8%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>6%</td>
</tr>
<tr>
<td>Urogynaecologist</td>
<td>5</td>
<td>5%</td>
</tr>
<tr>
<td>Gynaecologist</td>
<td>3</td>
<td>3%</td>
</tr>
</tbody>
</table>

Note: Respondents were able to select more than one category for this question, so the total is greater than 100%.

This suggests a high level of utilization of continence nurses over other health professionals for continence problems in the aged care area. It cannot be presumed that the assessment pattern of ACAT clients is reflective of the general population, given the access of ACAT clients to a multi-disciplinary team that often includes a continence nurse.
Respondents to the Health and Community Worker questionnaire were asked which professional groups they thought should have responsibility for assessing and treating incontinence. Not surprisingly, most of the GPs included GPs in their nominations and most community nurses nominated nurses amongst the preferred professional groups.

In total:
- 33 respondents nominated GPs;
- 27 nominated nurses and a further 10 nominated continence nurses;
- 17 nominated physiotherapists;
- 7 nominated urologists;
- 4 nominated gynaecologists or urogynaecologists;
- 2 nominated colo-rectal surgeons; and
- 2 nominated geriatricians.

Several respondents specifically referred to the need for a multi-disciplinary or team approach to continence assessment and treatment.

There was concern that standard hospital assessments do not explore incontinence in sufficient detail.

> “Hospital patients are sent home incontinent with no management plan. ‘Patch up’ strategies are used, such as pads. This reinforces the belief that nothing can be done.” (Focus group participant)

Better assessment forms and processes that encourage health workers to discuss continence issues, and guidelines for health workers on how to raise, discuss and assess continence problems were suggested. One specific suggestion was the inclusion of continence assessment as a standard item in health assessments for elderly people and other at risk groups.

Setting the scene for discussing incontinence and providing environmental cues and messages were considered important. Such strategies might include posters, pamphlets and videos in doctors waiting rooms, reinforcing to patients that incontinence is something they should talk to their doctor about.

### 4.6.3 Referral

Knowing when to refer and what services/specialists to refer people with continence problems to was another important factor identified by stakeholders.

It was suggested that there is a lack of networking and communication between continence specialists and services and a need for more multi-disciplinary awareness and collaboration.
Respondents to the questionnaire for Aged Care Assessment Team members were asked what proportion of their clients with continence problems they referred to a continence specialist or continence nurse advisor.

The responses suggest that over half of the ACAT members refer more than 50% of their incontinent clients for further assessment or treatment. Respondents to the Health and Community Worker questionnaire were asked in what circumstances would they refer a client for specialist assessment or treatment of their incontinence. The answers ranged from social reasons to medical/surgical indications and included:

- “Major change in voiding pattern or faecal problems that have not been managed by nursing staff.”
- “When socially unacceptable to the patient and simple treatments have failed.”
- “Female incontinence not responding to initial treatment.”
- “1. In most instances if wearing protections most days.
2. For pelvic floor exercises/urodynamic assessment.
3. If not responding to simple exercises, vaginal hormones, treatment of UTI etc”
- “Unknown cause of incontinence. Aids and exercises and behaviour modification unsuccessful. Particular diagnosis where perhaps medications could assist eg Parkinsons.”
- If conservative measures have failed or significant prolapse contributes to the incontinence.”
- “Depends on client’s age, medical history etc as to whether warrants referral – assessment made individually.”
- “When incontinence is interfering with life and not responding to any treatment I can offer or if it has a surgically remedial cause.”
- “When assessment demonstrates physical indicator(s) ie retention, haematuria, prolapse, renal issues.”
- “Person under 70 years.”
- “Anyone who hasn’t been assessed properly.”

The mention of age as a factor in referral decisions by several respondents is notable and may indicate a perception that incontinence in older people is not treatable.

Health and Community Worker questionnaire respondents were then asked to what type(s) of specialists they would refer a client with continence problems. The most frequent responses were urologists, gynaecologists, urogynaecologists, physiotherapists and continence nurse advisors.

One urologist interviewed for this project estimated that he referred one third of his patients to a Continence Nurse Advisor (CNA) and did not need to see them again for further treatment. He concluded that the majority of these patients could have been referred direct to the CNA by the GP.

4.7 Encouraging the Reporting of Continence Problems

Focus group participants were asked what could be done to help people feel more comfortable and confident about talking to a doctor or other health worker about continence problems. The suggestions included:

- Conduct a national ongoing multimedia campaign of community education so people feel more comfortable talking about continence problems. (Comparisons were made to community education campaigns for issues such as breast screening and Pap smears).
- Provide guidelines for health workers on how to raise the issue, what questions to ask and how to assess continence problems.
- Encourage and facilitate contact with continence nurse advisors and other appropriate services.
- Provide the option of anonymous disclosure initially, eg through a phone helpline to encourage people to start discussing the issue.

“We need to be positive – that something can be done – that incontinence may not always be cured, but it can be helped. We need to acknowledge that it is a common problem and that it is an embarrassing issue to discuss.” (Focus group participant)
4.8 **Issues for Aboriginal and Torres Strait Islander Peoples**

During the course of this research project, we consulted a range of individuals and groups concerned with the provision of continence services to Aboriginal and Torres Strait Islander peoples, including:

- the National Aboriginal and Torres Strait Islander HACC Reference Group – Continence Sub-Committee;
- Aboriginal health workers; and
- health workers from community nursing services and Aged Care Assessment Teams providing services to Aboriginal people in urban and rural/remote locations.

These consultations and responses to the questionnaires identified a range of issues and suggestions in respect of under-reporting of incontinence and access to continence information, services and treatment for indigenous Australians.

There are a number of reasons why Aboriginal and Torres Strait Islander peoples might not report their continence problems to a health worker or seek other assistance or treatment. Some of the issues for Aboriginal and Torres Strait Islander peoples (for example, embarrassment in discussing continence problems) are similar to those experienced by other Australian cultural groups. However, in many cases the issues are compounded by traditional cultural mores, and socio-economic and environmental factors.

It was noted that issues may be different for Aboriginal people in urban areas compared with those in more traditional communities.

The Aboriginal Development Officer of *Carers NSW* outlined a number of barriers and reasons for under-reporting. These included:

- lack of Aboriginal-specific resources on continence;
- embarrassment;
- fears that ‘bladder problems’ are associated with cancer;
- low literacy levels; and
- greater likelihood of living in rural and remote communities where services are unavailable.

**4.8.1 Gender, Age and Kinship of the Health Worker**

As with non-Aboriginal cultures, there is sensitivity about discussing continence problems with a health worker of the opposite gender. For example, a female may not wish to talk to a male health worker and men may not be willing to talk to women about these things. The cultural issues associated with Aboriginal men reporting their continence problems to female health workers was raised repeatedly in our consultations. It was suggested that this cultural sensitivity was more acute in older age groups.
For Aboriginal people, it may also be inappropriate for an elderly Aboriginal person to discuss these issues with a young health worker. So even when the health worker is male, older men may still be reluctant to discuss their continence problems.

“Remote traditional Aboriginal clients often don’t report and then may be reluctant to discuss or use products. Issues with having predominantly female staff – limited ability to assess males.” (Aged Care Assessment Team questionnaire respondent)

“Extreme embarrassment for Aboriginal people. Not mentioned in the older male generation.” (Continence nurse responding to questionnaire)

“With Aboriginal clients, it is difficult for male clients to discuss incontinence with a female health worker or female relative.” (Service provider focus group participant)

One of the groups we consulted described the Aboriginal moiety or skin system (eg ‘poison cousin’ issue) where people may not be permitted to talk to certain other people.

The importance of selecting the right person/people to discuss continence issues with Aboriginal people was emphasized and the following suggestions were provided:

- choose the right person to provide continence education in each community eg a younger person to talk with youth and an older person to talk with elders;
- use older people to facilitate discussion;
- remember that sometimes the health worker may not be the best person for local Aboriginal people to talk to; and
- always have a back up person when visiting an Aboriginal community to discuss continence problems, for example a person of the opposite gender, or if you are young, an older person.

4.8.2 Understanding and Knowledge of Incontinence

Stakeholders reported that a lack of understanding and knowledge about incontinence is a major reason for under-reporting of continence problems in Aboriginal and Islander communities.

It was suggested that Aboriginal people often think that incontinence is an inevitable part of ageing.

A need for education about incontinence was identified. Priority messages suggested for Aboriginal and Torres Strait Islander community education were:

- incontinence is a common problem but it can be cured or treated; and
- incontinence is not a normal part of ageing.
4.8.3 Shame and Shyness

An issue that appears to be present across all cultures in Australia is embarrassment. The people we consulted consistently referred to shame issues and shyness for Aboriginal people when talking about body functions.

One of the service provider focus groups noted that continence problems don’t get reported in Aboriginal communities and suggested that one of the reasons was that incontinence was seen as “something to be endured.” Another aspect was the “shy Aboriginal culture” with Aboriginal people “reticent about seeking help.”

As was reported for non-Aboriginal elderly people, fear also appears to be a factor. One health worker suggested that some Aboriginal people, particularly those living in more traditional remote communities, feared being placed “out of their country” (for example in a nursing home in town) if they admitted to a continence problem.

4.9 Issues for Ethnic Communities

This research project aimed to identify whether there were any major differences in the reasons for under-reporting of continence problems across the range of cultural groups present in Australian society. To this end, consultations were conducted with a broad range of health and continence service providers working with ethnic communities and peak bodies with a special interest in multicultural health and disability issues.

4.9.1 Cultural Reasons for Under-Reporting of Continence Problems

The results of our consultations indicate that the major reasons for under-reporting of continence problems are very similar across all cultural groups, ie

• embarrassment and shame, with incontinence being a ‘taboo’ subject;

• assumptions that incontinence is an inevitable result of child-bearing and ageing and that nothing can be done; and

• lack of knowledge of the services and supports that are available.

“Embarrassment is an issue across the board for most cultures”
(Multicultural service provider focus group participants)

“We are in a rural multicultural area and have all the ethnic issues to deal with, but it seems that all cultures find incontinence culturally difficult to deal with.” (Health and Community Worker questionnaire respondent)

Having concluded that these reasons are generally found in all cultural groups, it is important to note that there are additional barriers and issues for people from ethnic communities in identifying their continence problems and seeking assistance with these.

The socio-cultural mores of ethnic communities may present difficulties for the person in acknowledging their continence problem and disclosing this to family or friends. They may fear rejection by their spouse or other family members, exclusion or inability to
participate in social or religious activities, and other repercussions. Denial of the continence problem was a common feature reported by many service providers in this area. Some service providers reported a great reluctance by some middle aged women to disclose their continence problems to their spouse.

As with people from all cultural backgrounds, the emergence of incontinence in older family members may threaten traditional family roles and require a role reversal with children needing to provide care for their elderly parents. Loss of independence and status within the family and community structures can be quite devastating effects of incontinence.

“It’s an admission of decreased competence, regression to childhood - a self esteem issue.” (Multicultural service provider focus group participant)

“Some people are very adept at hiding the problem by changing their lifestyle – for example, they stop coming to respite, social activities, etc.” (Multicultural service provider focus group participant)

Focus group participants noted the family-centred culture of many ethnic groups and the limits this may place on social contacts and networks. This may present difficulties for the person with continence problems in having someone unrelated to their family who they can confide in.

“In other cultures, people may normally seek help with problems from their family first, but incontinence is a taboo subject.” (Service provider focus group participant)

“People from culturally diverse backgrounds tend not to seek help or advice about incontinence. Assumed that women will provide care and will put up with continence care issues.” (Service provider focus group participant)

The relative importance with which a person views their continence problems is also an issue. For migrant refugees, for example, who may have experienced great trauma and deprivation prior to arriving in Australia, continence problems may be viewed as very minor issues compared with recent events. For new arrivals in general, the challenges of finding accommodation, employment, education for children and settling in to a new community may overwhelm the need or desire to seek out assistance for incontinence.

Expectations of the health service system may also be low when people have emigrated from countries with poor health infrastructure, where even basic health needs are not met. They may never have heard of such a thing as a continence clinic or of specialist workers such as continence nurse advisors. Their experience of health care may have been more of a reactive response to serious health crises than a proactive, preventive approach to good health. People may not even identify their incontinence as a health problem for which treatment might be available.
Our consultations have suggested that even for people who have lived in Australia all of their lives, the onus of reporting incontinence is very much on the person with the incontinence problem or their carer. It has been suggested that incontinence is rarely included in general health screenings and that health workers are reluctant to initiate discussion on this issue unless there are significant indications that the patient has a problem in this area. Consumer-initiated reporting of a sensitive issue such as incontinence assumes a level of confidence and communication skills that may be challenging enough for a reasonably self-assured person within a familiar social/cultural environment. The challenge is obviously far greater for a person contending with an unfamiliar language, culture and service system. As one focus group commented:

“Ethnic women tend not to self-refer, ie they don’t seek help on their own initiative and are reliant on referral by a GP or community nurse.”
(Multicultural service provider focus group)

“They don’t know how to talk about it – how to get started, what words to use.
Are service providers asking the right questions in the right way?”
(Multicultural service provider focus group)

One focus group noted that faecal incontinence was much more difficult to talk about than urinary incontinence for people of any cultural background.

Confidentiality was also cited as a reason for not disclosing continence problems with one person suggesting that: “you would not want others to know that you have this problem in a social or work context where your competence is important”.

Lack of information and misinformation were also nominated as reasons for under-reporting in ethnic communities. Misinformation may emanate from health workers (eg that nothing can be done) or from discussion with families and friends (incontinence ‘myths’).

One service provider suggested that incontinence was less likely to be reported if the onset was gradual. Fear of being examined and fear of surgery were also noted in respect of ethnic communities (as these factors were in our general consultations). One group asked: “how much does the medical model put people off?”, for example they may assume that surgery is the only treatment.

**Age and Culture**

Cultural issues may be more pronounced in older age groups and it was suggested that providing continence information and services to the older generation may require quite different strategies to those used for the younger generation. Younger people (from whatever cultural background) tend to be better educated and have higher literacy levels than their elders and this needs to be considered when distributing written information, even when this is a translated version.
4.9.2 Issues for Specific Cultures

We asked participants in our focus groups and interviews whether there were any specific issues for particular ethnic groups. Although some specific issues were identified that might predominate in a particular culture or ethnic group, stakeholders also made the important point that we need to avoid generalizations i.e., that all people of a particular cultural group have the same attitudes to incontinence and face the same issues and barriers. There is great diversity within cultures and age groups and there is a need to consider each person individually for all cultural backgrounds.

The culture-specific tendencies suggested by stakeholders and outlined below, therefore need to be viewed with the issue of individuality in mind. It was suggested that:

- People from some cultural backgrounds may be more reluctant to report continence problems than others. This may in part result from whether incontinence is generally viewed as ‘normal’. In cultures where incontinence is not accepted as a normal part of ageing, people are more likely to seek help.
- Some cultural groups have a fear of anything medical e.g., fear of surgery, and hospitals.
- People’s experience of the health system in their country of origin may influence their expectations regarding Australian health services and about what problems they should seek help for.
- A lot of cultures don’t access generic services because they deal with the problems (and in some cases get good support) within their own communities.
- Some people will talk about continence problems if they are approached in the right way, for example, talking about more general health issues first as a group, with people able to come back individually later and ask for more information.
- Many will not report the problem until it is unmanageable (e.g., unacceptable odour).
- Women from some cultures may not even tell their husbands about their continence problems and vice versa. They have difficulty in discussing these issues with someone of the opposite gender.
- In cultures where the older male is head of the household, seeking help may be seen as admitting failure.
- In patriarchal societies where ‘manliness’ is very important, admitting to incontinence may be seen as having negative social consequences. Men from such cultural backgrounds may be more receptive to advice from a male continence advisor.
- Female circumcision may be an issue for Islamic women and African women. This can result in continence problems and other more major problems e.g., faecal fistula. Problems are seen in midwifery.
- Many cultures feel that continence problems should be handled within the family and there are expectations on women, as carers, to manage these problems.
• Many Muslim women will not deal with male doctors and there is a lack of supports for Muslim women.

• People from Asian cultures may blame their incontinence on certain foods, not their body - concept of ‘hot’ and ‘cold’ foods. They may try and balance these foods to reduce continence problems.

• Some communities have a general fear of government and the service system in general. Some will not even access Centrelink.

Cultural differences were also noted in the use of continence aids and appliances, with some groups using old sheets etc to manage incontinence and washing and reusing these continence materials. Some people may not be willing to use disposable products. Men from some cultural groups will not use continence aids as these are seen as ‘women’s or baby’s things’.

4.9.3 Role of Health Workers

The need for health workers to use appropriate communication and questioning techniques and terminology was raised by several groups and individual stakeholders.

Across all cultural groups, the importance of the response from the doctor or other health worker was highlighted. Focus group participants questioned whether doctors and other health professionals actually know what treatment is available for incontinence. One group reported that “What do you expect at your age” is a common response from GPs. There was also concern that if the doctor says that nothing can be done, then a barrier is set up for future reporting of the problem to other health professionals who could help the person.

“People are unsure how the doctor will respond:
- will they be put down?
- will they be made to feel foolish?
- will their problem be trivialized?”
(Multicultural service provider focus group participant)

The gender of the health professional is an important consideration for all cultures and even more so for Muslim women.

It could be assumed that the better a person gets to know their doctor, the more comfortable they would feel about discussing sensitive issues like incontinence. However, in close-knit ethnic communities, the reverse may be true.

“Some people have known their doctor for so long, they wouldn’t dream of raising the issue of incontinence with them - they might more readily tell a stranger, but don’t want to change doctors. For example, in some cultural groups, they may know the doctor socially.” (Multicultural service provider focus group participant)
The groups and individuals we consulted made a number of suggestions to help people feel more comfortable about discussing continence problems with a health worker:

- Set the scene and social context to support talking about incontinence;
- Ethnic community workers and other allied health workers need to be aware of continence problems and need to raise the issue and ask the right questions.
- Health workers need to develop trust before asking continence questions - they need a process to ask non-confronting questions - it may not be just whether you ask these questions but how you ask them and follow through on hints/suggestions that there might be a problem.
- Allow additional time and assistance for people from other cultural and language backgrounds to talk about continence problems.
- Subject of continence problems needs to be broached in a culturally appropriate way.
- Need a setting where people feel comfortable - eg non-threatening environment, ‘their turf’.
- One option might be to introduce the topic as part of health issues in multicultural English classes.
- Continence could be covered under the more generic heading of ‘Women’s Health’ or ‘Men’s Health’ rather than as a program on its own.

“Need to develop trust and rapport - people may ‘test’ the ground before they raise the really important issues. People will tell their stories the way they want to tell it.”  (Multicultural service provider focus group participants)

Service provider focus groups and questionnaire respondents were concerned about the use of family members as interpreters when continence issues were discussed. It was felt that younger family members may not be able or comfortable with relaying information about incontinence and this discomfort would also be felt by the older person for whom the information was being translated.

“An Arabic speaking woman was unwilling to mention her incontinence problems in front of her son but was willing to talk about them when there were only women in the room.”  (ACAT questionnaire respondent)

### 4.10 Summary

The results of our consultations have identified reasons for under-reporting of continence problems that are consistent with the findings of the research literature in this area.

By and large, there are three major reasons that appear to account for the majority of under-reporting behaviour evident in all major Australian cultural groups:

- the embarrassment and social taboo associated with incontinence;
the myths and lack of knowledge about incontinence (for example, the belief that incontinence is a normal part of ageing and an inevitable consequence of childbearing); and

the reluctance and lack of specific skills of many health practitioners to raise and effectively address this issue with their patients.

Additional concerns were described for elderly people, particularly fear of being placed in residential care if their continence problems were revealed. The carer, rather than the person with the continence problem, is often the one who actually reports the problem to a health worker.

Although there were conflicting accounts regarding the effects of age and gender on reporting behaviour, the general view was that the social and cultural barriers to reporting continence problems were stronger in the older population and in the male gender.

Particular cultural and religious sensitivities in respect of the reporting and management of continence problems were identified.

Our consultations have found that many people are reluctant to approach their general practitioner about continence problems due to a combination of embarrassment, other fears, lack of knowledge about incontinence and treatment options, and considering the problem not sufficiently important to take up the GP’s time. General practitioners and other first line health workers have an important role to play in overcoming these barriers to disclosure and in providing an appropriate response when continence problems are reported to them.
5.0 Access, Affordability and Barriers to Continence Services and Treatment

5.1 Introduction

The requirements of this research project included assessment of the physical barriers to seeking treatment and the collection of qualitative information about the accessibility and affordability of continence aids and appliances services.

These issues are important to the examination of reasons for under-reporting of incontinence. People with continence problems may avoid or defer seeking assistance if they are not aware of the services and treatment options that exist, services are not physically available and accessible in their local area, services are not affordable and/or the services are not ‘user-friendly’.

Our consultations therefore explored issues of access and affordability of continence information, services and treatment for all cultural groups and any other barriers to accessing continence services and treatment.

5.2 Access to Services and Treatment

Questionnaire respondents were asked whether they considered the people they assess or treat (and for peak bodies and advocacy groups, the people their organisation represents) had received adequate and appropriate assistance in respect of their continence problems. Five categories of assistance were presented for questionnaire respondents to rate with yes, no or unsure. The results for the no ratings are summarized in the following table.

<table>
<thead>
<tr>
<th>Number and % of no responses</th>
<th>Health &amp; Community Workers (n=66)</th>
<th>Specialist Continence Practitioners (n=14)</th>
<th>ACAT Members (n=101)</th>
<th>Peak Bodies &amp; Advocacy Groups (n=23)</th>
<th>TOTAL across all groups (n=204)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Information about incontinence</td>
<td>20 (30%)</td>
<td>3 (21%)</td>
<td>37 (37%)</td>
<td>10 (43%)</td>
<td>70 (34%)</td>
</tr>
<tr>
<td>B. Assessment of Continence Problems</td>
<td>25 (38%)</td>
<td>2 (14%)</td>
<td>41 (41%)</td>
<td>11 (48%)</td>
<td>79 (39%)</td>
</tr>
<tr>
<td>C. Assistance with day to day management of incontinence</td>
<td>20 (30%)</td>
<td>2 (14%)</td>
<td>42 (42%)</td>
<td>14 (61%)</td>
<td>78 (38%)</td>
</tr>
<tr>
<td>D. Access to appropriate continence appliances and aids</td>
<td>40 (61%)</td>
<td>5 (33%)</td>
<td>40 (40%)</td>
<td>12 (52%)</td>
<td>97 (48%)</td>
</tr>
<tr>
<td>E. Access to treatment (eg physiotherapy or surgical intervention)</td>
<td>28 (42%)</td>
<td>3 (21%)</td>
<td>46 (46%)</td>
<td>7 (30%)</td>
<td>84 (41%)</td>
</tr>
</tbody>
</table>
The types of assistance of most concern to each questionnaire group (ie those types of assistance with the most no responses) are highlighted in the above table. Across the total sample for all questionnaires, access to appropriate continence appliances and aids was the type of assistance most frequently rated as not adequate or appropriate, and this was followed by access to treatment.

Questionnaire respondents provided a range of written comments to support their ratings for this question. A selection of these comments appears below.

- "Lack of medical investigation and surgical treatment, medical information, staff education, local specialty and lack of advertising re services available.” (Health and Community Worker questionnaire respondent)

- 1. Assessment takes a long time and patient may not like the idea of paying for a longer consultation.
   2. Involved procedure – need to refer to community nurses, physio, specialist, investigations and frequent GP follow up.
   3. Often problems complicated by physical and mental frailty (Health and Community Worker questionnaire respondent)

- “Local continence advisor available but further specialist review eg urologist has long waiting period or travel to main city (500km).” (Health and Community Worker questionnaire respondent)

- “Patients need a diagnosis that is accurate – they also need education and empowerment over the problem so they know:
  1. what caused the problem
  2. what lifestyle behavioural changes they can make to help treat the problem – people can do much to help their own recovery
  3. many patients have no idea which is the best surgical treatment and end up with 2-3-4 operations – with little or no education.” (Specialist Continence Practitioner questionnaire respondent)

Three questionnaire respondents were concerned that conservative treatment is often not tried first and one suggested that inappropriate surgery was being performed.

Members of Aged Care Assessment Teams responding to our questionnaire provided estimates of the proportion of their clients with continence problems who had ever had treatment for their continence problem. The majority of respondents (57%) estimated that no more than a quarter (25%) of their clients had ever received treatment, only 21% of respondents estimated that more than 25% had received treatment, and 23% of the respondents were unsure what proportion of their incontinent clients had received treatment.

When asked if they had observed any gaps or unmet needs in the continence-related services available to their clients, 71% (72) of the Aged Care Assessment Team members responded yes, 16% (16) responded no, and 13% (13) were unsure.
Consumers and carers reported a range of difficulties in accessing continence information, services and treatment. A general lack of people trained to provide continence services across the country and particularly in remote areas was reported by many questionnaire respondents and focus group participants. Some service providers in urban locations reported that there were no continence clinics as such in their area, with a reliance on visiting specialists with an interest in continence. Where continence clinics were present, it was reported that these may only operate for one day or morning per week, resulting in long waiting lists and delays.

Stakeholders were concerned about the complexity of the service system and the variations in services and eligibility from one service to another, resulting in service gaps for some groups.

“There is fragmentation of service providers, for example, different eligibility, limited geographic boundaries, consumer criteria, and priorities, etc. This results in gaps in services for particular client groups, such as younger people.” (Service provider focus group participant)

Many respondents called for an increase in the number of continence practitioners and services, particularly in rural areas.

“The primary aim should be to increase services at the grass roots level. We need more Continence Nurse Advisors. If continence problems are picked up early enough and can be treated and controlled, the more complex cases can be referred to specialists. We should increase the number of baseline therapists.” (Urologist participating in telephone interview)

Some questionnaire respondents also described a shortage of children’s continence services. One respondent reported that their local enuresis clinic had closed leaving a significant service gap, and one continence nurse reported that children’s continence problems used more than 60% of her clinic’s time and resources.

Lack of equipment for urodynamic testing and lack of funding for the purchase of bladder scanners were also reported.

One consumer organisation described the lack of access to assistance for home modifications, describing the circumstance of a mother attempting to care for her wheelchair bound but now fully grown teenage daughter, with a bathroom doorway too narrow for a wheelchair to fit through and a toileting routine that involves the mother carrying her daughter into the toilet and having to stand and hold her on the toilet as there is no space for a toilet frame or wheelchair.
5.2.1 Rural and Remote Areas

Questionnaire respondents reported there were limited services in rural and remote areas, for example, no continence advisor available. Restricted access to physiotherapy services for public patients was also reported. Regular visits to rural and remote areas by continence advisors and specialist physiotherapists were suggested.

“There is a lack of services in (name of town). You have to go to the city and there are long waiting times to see a specialist.” (Consumer from a rural area participating in a telephone interview)

Other questionnaire respondents pointed to the difficulties in obtaining transport, the long distances that had to be traveled and the costs of travel, including the costs of overnight accommodation for people needing to access continence services in rural and remote areas.

“Distance is a barrier. People with continence problems may not be able to travel more than a few kilometers. Public transport may not be available. It may take a day to get to a major centre for continence assessment or treatment. In the wet season, they may not be able to get out of their communities at all.” (Service provider focus group participant)

5.2.2 Physical Barriers

Stakeholders reported a number of physical barriers to accessing continence services, such as:

- distance to continence clinics and services (as noted above, this presents a particular difficulty for those living in rural and remote areas);
- lack of transport for many consumers (particularly the elderly) even in urban areas;
- poor location of continence clinics in some hospitals, making them difficult to find and get to;
- inadequate equipment such as fixed height examination tables, step stools and no lifting equipment in GP and specialist consulting rooms making examination difficult for people with physical disabilities; and
- long waiting lists for many continence services and long approval times for assistance with continence aids.

The need to travel for continence assessment and treatment was cited as a major deterrent to accessing continence services for many consumers and carers, particularly those in older age groups.

“If they have to travel for further assessment, they are reluctant to do this.” (Health and Community Worker questionnaire respondent)
A number of ACAT questionnaire respondents commented on the need for services for housebound clients

“Not enough experts working in the field, and not enough who visit in the home.” (Aged Care Assessment Team questionnaire respondent)

### 5.2.3 Cost and Affordability Issues

Respondents to three of our questionnaires were asked if there were any issues for the people they assess or treat (and for peak bodies and advocacy groups, the people their organisation represents) in the cost or affordability of continence aids, appliances or treatment services.

<table>
<thead>
<tr>
<th>Cost or Affordability Issues for Clients</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health &amp; Community Workers (n=50)</td>
<td>36</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>(72%)</td>
<td>(12%)</td>
<td>(16%)</td>
</tr>
<tr>
<td>Specialist Continence Practitioners (n=14)</td>
<td>14</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(100%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peak Bodies and Advocacy Groups (n=23)</td>
<td>23</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(100%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL (n=87)</td>
<td>73</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>(84%)</td>
<td>(7%)</td>
<td>(9%)</td>
</tr>
</tbody>
</table>

Specialist continence practitioners and peak bodies/advocacy groups were universal in indicating that there were cost or affordability issues for consumers.

Questionnaire respondents referred to a number of concerns regarding cost and affordability. These concerns mainly involved:

- the cost of pads and other continence aids, particularly for pensioners and those ineligible for aids and appliance scheme assistance such as nursing home and hostel residents (Note that although high level care clients in aged care homes are entitled to receive continence aids without additional charge, low care residents can be charged);
- the cost of therapy services, particularly physiotherapy, but also pathology and radiology; and
“Even people who are employed and active find it expensive and have to work out their priority times that they will wear a pad.” (Specialist Continence Practitioner questionnaire respondent)

“People often use inappropriate management due to high cost of continence aids eg toweling cloths, small pads that are insufficient.” (Specialist Continence Practitioner questionnaire respondent)

Even in urban areas, the cost of continence assessment and services was reported to be expensive. One focus group reported that some people were asked to pay $400 for urodynamic testing. (Note that our research team questions why a fee of this magnitude would have been requested, given that urodynamic testing is covered under the Medicare schedule of benefits and the standard fee is usually minimal)

“The time and expense of assessment and treatment – it is hard to avoid the cynicism of thinking that this is just lining the provider’s pockets.” (Consumer focus group participant)

One peak body explained that the cost of incontinence was not just limited to the cost of continence aids and gave the example of families who have a child with incontinence who have to buy extra sets of school uniforms so that a change of clothes can be kept at school in case of accidents and leakages. Increased laundry costs were also cited.

It would appear that many of the cost issues associated with incontinence are not adequately addressed through private health insurance.

“Private health funds are slow/reluctant to fund CNAs and continence products.” (Specialist Continence Practitioner questionnaire respondent)

### 5.2.4 Access to Continence Aids and Equipment

Difficulties in accessing continence aids and equipment, particularly continence pads was the most frequently and strongly raised access issue for consumers and carers consulted for this research project. These concerns were reinforced by the peak bodies and advocacy groups and service providers.

“The inadequacy/indignity of needing to use general public “continence aids” such as those designed for younger children or menstruation is intolerable, and the alternative of scrounging subsidies from managed care and other programs is exhausting and a time-limited stop-gap.” (Submission from Carers’ Association of Victoria)

Lack of awareness of continence services and supports, including aids and equipment schemes on the part of GPs, community workers and HACC workers was cited as a barrier to access by one focus group. The Commonwealth Continence Aids Assistance Scheme (CAAS) and state aids and equipment schemes were described as “extremely difficult to access” and “too restrictive”.

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A lot of products are accessed (by the elderly especially) through pharmacies at a much greater mark up than in supermarkets or wholesalers => vulnerability of the elderly to pay high prices for convenience.” (Specialist Continence Practitioner questionnaire respondent)

Limited financial support to people for the purchase of essential aids can result in medical complications ie infections from re-use of disposable aids or wounds resulting from prolonged skin contact with excreta.” (Peak Body/Advocacy Group questionnaire respondent)

A particular issue for those living in rural and remote areas is the freight costs charged for delivery of continence pads and other aids outside of urban areas.

One service provider reported that people without credit cards may not be able to make phone orders for continence aids and equipment. Other problems with phone orders were also noted such as consumers not knowing what type of aids they require.

Some consumers reported a lack of information about continence aids and appliances and how to access these.

“I wouldn’t know where to buy them. The chemists only have female assistants. There is no-one here that you can sit down and talk to. You can’t sit down and talk to a doctor because they are too busy.” (Male consumer from a rural area participating in a telephone interview)

Concerns were raised for carers of people with dementia, particularly in respect of the cost of continence pads. One carer noted that people with dementia may live for 20 years and may be incontinent for half of this time. Another carer described the emotional and financial costs of caring for a physically disabled adolescent who is incontinent and said they could not afford the cost of modifications required to their bathroom.

(Note that there are schemes that can assist with home modifications eg the Home and Community Care Programme, assistance available through the Department of Veterans’ Affairs, disability programmes, and other assistance provided by community organisations. It may be that the problem is one of awareness of these sources of assistance and how to access them.)

Concerns were also raised about the lack of assistance with the purchase of continence aids and appliances for children.

On the positive side, some disability and carer organisations encourage their members to network to take advantage of cheaper bulk purchasing arrangements.

“We need to promote networks and support groups for purchasers of continence products and also to promote affirmative action and a consumer lobby.” (Consumer focus group participant)
5.2.5 Subsidy Schemes

Many comments were received suggesting inadequacy of the assistance available through Commonwealth and state/territory aids and equipment schemes. Some consumers felt that the application of a standard subsidy ceiling (for example $450 per annum for the Commonwealth’s CAA Scheme) regardless of severity of incontinence or type of aids required, was inequitable.

Consumers stated that the CAAS allocation of $450 per annum has not increased over the past five to ten years and that people lose any component of their allocation not used in a financial year. Consumers reported expenditure on pads ranging from $450 to over $1,600 per year.

“CAAS Scheme ceiling limit of $450 pa presents difficulties for many with high level disabilities eg many quadriplegics require over $1,500 worth of continence aids, particularly urinary aids pa. Urinary tract infections are a common occurrence due largely to reusing of products designed for single use.” (Peak Body/Advocacy Group questionnaire respondent)

“Why are subsidies ceased when people reach 65 years of age? Costs increase and income decreases from this age onwards.” (Consumer focus group participant)

“Incontinence costs them so much. It discourages people from returning to work as they are financially worse off.” (Service provider focus group participant)

A submission from the Australian Quadriplegic Association (AQA) presented the results of a survey of 100 of its members conducted in February 2000 to determine whether their CAAS allowances lasted them a full year. The results as presented were:

- 68% of respondents stated that their allowance did not last all year;
- 13% stated that they made their allowance last by restricting their usage;
- 57% of respondents ran out of supplies in 9 months or less;
- 53% of respondents supplemented their CAAS Allowance by using either PADP or other state based schemes;
- 69% of respondents found that their allowance did not last as long as it did five years ago;
- on average, respondents believed that they need a $700 CAAS allowance to cover their continence aids and equipment; and
- 66% used an ‘any other comments about CAAS’ opportunity in the survey to criticize the running of the scheme by its current operators.

AQA also expressed concerns that the transfer of CAAS funding from the Department of Family and Community Services to the Department of Health and Aged Care could see...
CAAS “lose its disability focus” and requested that an amount of CAAS funding be quarantined to ensure that the needs of people with severe physical disabilities are met.

A number of other issues were raised in respect of state/territory (eg PADP, ILEP) and Commonwealth government (CAAS) assistance schemes. The key concerns from peak bodies, advocacy groups and consumers were:

- the eligibility criteria of CAAS and state/territory schemes bar access by needy groups such as over 65 years olds, children (in some states), and (in some cases) those who are employed;
- lengthy waiting times for scheme approval were reported (waiting times of 6 to 8 months were reported for some state schemes);
- delays in delivery of supplies (particularly where interstate suppliers are used);
- allocations are standard and not based on individual needs;
- poor variety and quality of products available through state/territory government assistance schemes; and
- some continence aids, eg continence pads, are excluded from some schemes.

“I am aware of adults who could not remain in employment, as their wage made them ineligible for CAAS, but was not sufficient to live on and pay for all their continence supplies.” (Peak Body/Advocacy Group questionnaire respondent)

Note: The CAAS eligibility criteria provide for working people to access CAAS if they receive the Mobility Allowance. Adults accessing CAAS who are on DSP can receive $28,000 without affecting their eligibility. If they are in receipt of the Mobility Allowance, they can earn an unlimited amount without affecting eligibility.

One ACAT questionnaire respondent referred to recent reports that their state scheme would not supply continence pads to clients where the incontinence is related to a dementing illness.

We received several comments indicating difficulties for consumers in obtaining, using and understanding the CAAS catalogue. It was suggested that product catalogues should include pictures and detailed product information relevant to consumers such as absorption, odour control, practical tips, etc. The NSW PECS product catalogue was cited as a good example with this being high quality, in colour and indexed.

A further suggestion from one consumer was the introduction of a standard symbol system for rating pad capacity and speed of absorption.

The only consumer group who reported satisfaction was those entitled to Department of Veteran’s Affairs assistance which was described as “excellent” in respect of provision of continence aids and appliances.
Although the need to encourage responsible use of continence products and the use of subsidies rather than free provision of continence aids was recognized, the need for a more equitable system was stressed.

A nurse from an Aged Care Assessment Team suggested:

“There should be a scheme like the PBS for drugs, where pads could be prescribed by a continence advisor and purchased from an outlet on prescription.”

Concern about the operation of Australia’s aids and equipment schemes has been evident for some time. In 1996, as part of the evaluation of the Commonwealth/State Disability Agreement, Ernst & Young surveyed 171 government-funded aids and equipment service providers (including providers of continence aids assistance). The study concluded that the provision of aids and equipment for people with disability was “fragmented and lacking in access, equity, efficiency and accountability” (p. viii)

The system of aids and equipment schemes is complex and involves all state and territory governments and the Commonwealth government. The allocation of funding and the management of expenditure through these schemes is also far from straightforward. The level of consumer discontent conveyed to our research team suggests that there are significant problems for those requiring continence aids and equipment.

5.2.6 Gaps in Services and Supports

Concerns were raised that some groups are missing out on continence services and subsidies, for example:

- self-funded retirees;
- those aged over 65 and therefore ineligible for the Commonwealth government CAAS;
- females with urinary incontinence in some states where the state government scheme does not supply incontinence pads;
- children aged under 16 years not entitled to any assistance or subsidy for continence products in South Australia

“Systems which provide assistance should be the same for children and adults under a national scheme.” (Peak Body/Advocacy Group questionnaire respondent)

5.2.7 Continence Services for Older Australians

There appeared to be a general concern about a lack of continence services, particularly treatment and rehabilitation oriented services, for older people.
Timely, effective assessment of continence problems in a systematic way is lacking. Older people seem to be given pads, not thoroughly assessed and managed as appropriately.” (Aged Care Assessment Team questionnaire respondent)

Two peak bodies suggested that living in aged care homes may be a barrier to accessing services, commenting that: “older people in residential facilities do not receive preventative or therapeutic continence assistance” and “the emphasis in residential facilities is on management rather than trying to aim for continence”. Another advocacy organisation suggested that keep fit classes conducted in residential aged care facilities could include pelvic floor exercises.

“Community Health Nurse does not go into residential facilities and few if any facilities employ specialist continence nurse services. Reluctance of GP’s to treat the condition seriously and refer to a urologist.” (Aged Care Assessment Team questionnaire respondent)

One respondent suggested the fact that aged care homes are Commonwealth-funded is a barrier to state-funded continence nurse advisors providing services to residents of these facilities.

One service provider described a lack of community services “to support someone who is incontinent to live at home eg daily home visits for personal care.”

Advocacy groups also raised the issue of the cost of continence products for people living in ‘low band care’ aged hostels, with these people required to purchase their own products with what remains after 85% of their pension is deducted in residential care fees. Those classified as ‘high band care’ do get their continence aids supplied but one advocacy organisation had concerns some high band care facilities ration continence aids.

“Some high band care facilities ‘ration’ continence aids and clients are expected to ‘reuse’ pads which have been used but described as ‘not full!!’ after a shower.” (Peak Body/Advocacy Group questionnaire respondent)

One carer group argued for the provision of continence aids assistance to older age groups.

“Given that incontinence, particularly in older age groups, is a major trigger for entry into residential care, it is sensible for governments to provide a greater range of continence items to a wider range of people. This may help delay entry into residential care, which is obviously more expensive to provide.” (Peak Body/Advocacy Group questionnaire respondent)
5.2.8 Funding for Continence Services

Lack of funding for continence services and supports was raised repeatedly during our consultations by both consumer and service provider stakeholders.

“Is it because incontinence is a symptom, not a disease and not ‘glamorous’ that it doesn’t get funding or priority?” (Service provider focus group participant)

Long waiting lists for continence services were reported by many of the service providers we consulted.

“Community Nurse – ‘too busy for geriatric incontinence’. Only one CNC-continence for vast area health service.” (Aged Care Assessment Team questionnaire respondent)

“The continence advisor has a huge role in an ACAT team. Referrals are often placed in long waiting lists. Strategies to reduce these lists need to be explored eg increased staffing, streamlining referrals to improve efficiency by educating staff (identifying problems and prioritizing referrals).” (Aged Care Assessment Team questionnaire respondent)

Service providers from a number of states and territories suggested that the budgets of state programs for the subsidy of continence aids and appliances were not keeping up with the increasing demand for assistance.

Another issue was the lack of access to continence-related physiotherapy services through the public health system. One service provider described using community health services “as a cheaper substitute for physiotherapy.”

Service providers in one focus group suggested a lack of commitment and involvement from the hospital sector (both public and private) as most of the work in this area was being done by community health workers. They questioned why funding was not directed to the community health sector for this work and asked if this issue was linked to hospital casemix funding. One consumer reported a cutback in hospital provision of specialist continence nurse advice and difficulty in finding other sources of advice.

5.2.9 Other Barriers to Services and Treatment

The general complexity of continence assessment and referral processes were described as a barrier by some questionnaire respondents.

“Delays in assessment, difficult referral process – people give up.” (Aged Care Assessment Team questionnaire respondent)
Access to facilities to assist with management of incontinence was also important to many of the stakeholders we consulted. Practical issues include a lack of facilities in public toilets for managing continence problems and ‘accidents’.

Low literacy levels were cited by a range of stakeholders as being a major barrier to accessing information about incontinence and continence services and a general barrier to accessing health and community services overall.

Mobility and dexterity problems were seen as barriers to accessing (ie getting to) health services and continence clinics and as barriers to self managing continence aids and equipment.

Cognitive impairment was also reported to be a significant barrier, restricting the person’s ability to understand information and self-manage or participate in treatment.

### 5.3 Access Issues for Indigenous Australians

Many of the stakeholders we consulted described a general shortage of services for Aboriginal and Torres Strait Islander people, including:

- insufficient health workers accessible to the Aboriginal population (particularly in rural and remote communities);
- health workers not trained in continence assessment and treatment; and
- lack of access to specialized continence practitioners for Aboriginal people living in remote communities.

One group suggested that health workers are having to deal with basic issues like housing, food, etc and these may take priority over continence problems. Another described an absence of continence services in their remote region and the cost of having continence specialists travel there to see patients and provide training for health and aged care workers.

It was suggested that doctors treating Aboriginal people still need education and that some are accepting incontinence as an inevitable part of growing old. A tendency for Aboriginal people to stay with the same doctor “even if the doctor doesn’t believe or understand them” was described, meaning that some people with continence problems might never receive appropriate assessment and treatment.

An Aged Care Assessment Team member described difficulties in providing regular continence services (for example, follow up and bladder scans) in remote Aboriginal communities. An absence of specialist services (eg visiting specialists) for these remote communities...
communities was also an issue. Another difficulty encountered by this worker included problems in achieving compliance with medications and interventions. The cost of products was described as “prohibitive” for “an already financially disadvantaged population”.

One focus group suggested that remote Aboriginal communities lack access to general information (such as that provided by television advertising) about continence products. The range of continence products available in Aboriginal community stores was described as “limited”.

One group asked what strategies should be used for youth and preventative approaches? Another group for whom continence services seem to be lacking are young disabled Aboriginal people and those with injury-induced continence problems (eg paraplegia resulting from motor vehicle accidents).

5.3.1 Cost of Continence Aids and Appliances
The cost of continence aids and appliances was of concern for service providers working with Aboriginal communities. The main issue appeared to be cost acting as a deterrent to the use of continence aids and appliances. The points raised by stakeholders in this respect were:

- The cost of continence aids and appliances may deter some people from using these.
- There is a cost factor. Health issues may come last if the person has a low income. People may not use continence aids/appliances if these cost money.
- It is difficult to recover the cost of continence products from people.

5.4 Access Issues for Ethnic Communities
We asked multicultural continence service providers and consumer groups about the barriers that people from ethnic communities face in accessing continence information, services and treatment. Some of these barriers (for example, rural and remote issues and cost of continence products) were present across all cultural groups. Others were additional issues faced by people who do not have English as their main language.

“Getting through the various information services and referrals can be a long and complex process – particularly for people who don’t have a good command of English.” (Service provider focus group participant)

Poor access to information further contributes to lack of awareness of continence services and a poor understanding of why and how to seek help. The information needs of ethnic communities are discussed further in section 6.3 of this report.

A key access issue for many newly arrived migrants and refugees is the lack of access to health services that use interpreters or speak their language. For women with continence problems, particularly Muslim women, access to a female health practitioner may be very important.
5.4.1 Access to Continence Products

Several health workers described difficulties in accessing continence products and subsidy schemes for ethnic clients. For example:

- “It is difficult to explain to people from some cultures that they have to pay for any additional supplies”
- “Some people have difficulty understanding the concept of a ‘subsidy’”.
- “Some people have an expectation that they will get what they want (eg continence aids) because friends and relatives get them.”

One service provider questioned whether the focus is too much on continence products rather than on the underlying cause of the incontinence and its treatment.

5.4.2 Rural and Remote Issues

A range of barriers for multicultural families living in rural and remote locations were described, including:

- Isolation, transport and cost issues.
- Confidentiality issues in small communities.
- Poor availability of incontinence products and delays in delivery.
- Lack of support and information for carers.
- Increased reliance on children and other family members as interpreters.

Stakeholders suggested a number of strategies to redress these problems:

- Continence and cultural awareness training for rural health workers.
- Support of family workers and support networks for carers (eg through use of mobile continence assessment and advisory teams, Telelink etc).
- More training and information for ethnic communities.
- Better use of technology.
- A service directory of all continence service providers, including those in rural and remote areas.
- Encouragement of partnerships and linkages between service providers.
- Improved linkages between continence advisors and ethnic and rural GPs.
- Development of trusting relationships between ethnic communities and continence advisors eg through attending ethnic community events, linking with ethnic sport and recreation groups, and working with religious leaders.
5.5 Summary

This section has reported the views of stakeholders regarding access to continence information, services and treatment and barriers to accessing services and other assistance such as availability and affordability.

The presence of adequate and appropriate continence services and resources is an important factor in community and health practitioner awareness of the assistance available for continence problems. The service and resource environment may play a significant role in changing people’s attitudes to incontinence, for example by promoting awareness that incontinence can be treated, improved or better managed. The more people who successfully access appropriate and effective continence services and assistance, the further the message is spread that practical help is available. This in turn provides people with a reason to report their continence problems and seek assistance.

Stakeholders consulted for this project through our focus groups, interviews and questionnaires have identified a number of concerns and access barriers. The main issues identified were:

- concerns about access to appropriate continence appliances and aids;
- inadequate access to continence information and treatment options;
- shortage of continence clinics and trained continence practitioners in some locations, particularly in rural and remote areas;
- travel requirements to access continence treatment deterring treatment seeking;
- high cost of continence pads and other aids and some services including physiotherapy;
- strong concerns from consumer representatives about the adequacy and eligibility requirements of aids and equipment subsidy schemes;
- reported lack of continence services, particularly treatment and rehabilitation oriented services for older people and indigenous Australians;
- reports of long waiting lists for many continence services; and
- information barriers to seeking and accessing continence services for ethnic communities.
6.0 Information Needs

6.1 Introduction

Information needs were raised repeatedly during our consultations with both consumers and carers and service providers. The brief for this project required our consulting team to: “collect information from carers and community workers about effective means of providing them with relevant information and training in both areas of incontinence (urinary and faecal).”

The provision of appropriate information is a particularly important tool in addressing under-reporting of continence problems. Information is the key to addressing the attitudes described in many of the research studies we reviewed earlier in this report (Section 3). The results of our own consultations with consumers, carers and community workers (ie the assumptions that incontinence is a natural consequence of ageing and childbearing and that nothing can be done about it) also indicate the need for community education. People need to know that incontinence is not a normal condition, although many people have continence problems, and that assistance and effective (and in many cases, inexpensive and non-invasive) treatment is available. Consumers, carers and those who assist them also need to know where and how to access continence services.

The stakeholders we consulted readily identified the type of information that would be relevant for them and that would encourage people with continence problems to seek assistance.

This section of the report describes the information needs of consumers and carers. Section 7 then details the information and training needs of health practitioners and community workers.

6.2 Consumer and Carer Information and Training Needs

Both service providers and consumers identified a need for more information about incontinence and the continence services that are available.

“The continence services that are there are ‘best kept secrets‘.” (Focus group participant)

It was suggested that continence services may not want to promote themselves for fear of not being able to meet demand and expectations.

Consumer groups considered that awareness of continence services was generally poor. One consumer representative suggested that “the pad suppliers have done a good job of making people aware that continence pads are available at the supermarket” and that a similar campaign is needed in respect of continence information and treatment services. Many of the consumers and carers we consulted reported that they had not seen any specific information on incontinence and that there generally wasn’t much printed information available.
“We receive a huge number of calls on the Dementia Helpline about continence issues – people obviously don’t have the information.”  
(Consumer focus group participant)

“Families say they are given very little information about possible causes of incontinence, personal aids or equipment that can help manage the problem, treatments that are available or strategies they can adopt to minimize associated difficulties.”  
(Submission from the Carers’ Association of Victoria)

Although some participants acknowledged that awareness was increasing among some groups, it was considered that much more needed to be done.

When asked what information or education people with continence problems and their carers require about continence problems and continence services, focus group participants identified the following needs:

- to understand what continence problems are and how common these problems are;
- to know what is normal;
- to know that incontinence is a treatable condition and that it is not an inevitable part of growing old;
- to know where to go for help and information (e.g. know the Continence Helpline number);
- to know what services are available and how to access these;
- to know that a lot of the services are free;
- to know about the treatment options that are available (including non-surgical options);
- to know the range of products that are available and where to go to access these;
- how to use products and how to select the best product;
- to know about simple interventions such as bladder retraining, before resorting to pads, uridomes, etc.

“We need access to information to tell us what the problem is. We need to know all the alternatives to surgery. (Most men are terrified of prostate problems – they don’t want surgery). We need to know what incontinence is and how to deal with it. We need a men’s health clinic available locally and after hours.”  
(Consumer participating in a telephone interview)
“People with continence problems need:
- a sympathetic ear;
- proper diagnosis; and
- frank advice.”
(Consumer participating in a telephone interview)

One stakeholder noted that information about continence aids and equipment schemes was not actively promoted to clients or professionals.

The importance of having appropriate training materials and resources for educating and informing consumers was emphasized. One example given was flipcharts “so you can show the person what you’re talking about.”

Peak bodies and advocacy groups had further suggestions regarding unmet information and training needs for consumers and carers:
- training in the use of continence aids;
- continence assessment and training at home;
- community services that can reduce the impact on the carer and family (e.g., home help with laundry);
- information for older people, particularly men, looking after a partner; and
- a listing of all continence service providers.

“There needs to be an accessible, up to date database listing of continence advisors on a state by state basis, so organisations such as ours can refer on to the appropriately trained local specialist.” (Peak Body/Advocacy Group questionnaire respondent)

“Carers could benefit from training in continence management strategies that are tailored to their specific care situation, delivered either in a 1:1 or small group approach. For example, condition specific such as dementia or stroke, or age specific, e.g., teenagers and young adults. Similarly, community workers need training in strategies appropriate to clients in their sector or organisation.” (Submission from the Carers Association of Victoria)

One organisation also noted that people who were not on the CAAS scheme have limited access to information about where to obtain continence supplies.
Carers NSW offered the following information from their own research:

Carers generally lack information about the full range of services that are available to assist them or the person they care for, and this includes incontinence services. Previous research done by Carers NSW (“Coping at Home: Carers’ Use and Non-use of Community Services”, 1998) shows that information about community services must be offered to carers, rather than waiting for them to ask for it. This applies equally to information on incontinence... The same research also showed that information needs to be delivered personally, where possible, so that it can be tailored to the needs of the individual carer. Health professionals, in particular, are important contact points with whom carers and care recipients often come into contact. Thus, we would argue, they are ideally placed to offer information on incontinence aids, appliances and treatment.

Service providers responding to the questionnaires also identified the need for more information and training materials for their clients. Service providers requested:

- simple leaflets;
- a video;
- general public awareness and information campaign;
- more public education (and education for medical and nursing providers) about conservative treatment options;
- information about how to access continence advisors and other sources of help and information; and
- continence promotion activities.

“Patients need to be educated about treatment options open to them. Surgery should be the last choice.” (Specialist Continence Practitioner questionnaire respondent)

The link between providing information and having appropriate services available was raised ie it is important that when consumers are provided with information about services, the services are able to respond.

“I can provide information but there aren’t enough people/services to follow up with ongoing training.” (Health and Community Worker questionnaire respondent)
6.2.1 Distribution of Continence Information to Consumers and Carers

Consultation participants made a number of suggestions for disseminating information to consumers and carers:

- Include information about treatment options in advertising for continence products.
- Ensure doctors and other health workers receive information about the available treatment and product options.
- Provide more pamphlets, posters (prompting people to talk about their continence problems with their GP) and other information about continence problems in doctors’ waiting rooms and for health professionals to hand out to patients.
- Have a continence video library for GPs to use with patients.
- Provide information for busy people to get self-started with preventative action.
- Provide information for carers through information packages, workshops, etc.
- Use the Internet.
- Develop links between the various Helplines.
- Develop simpler versions of written information, for example cartoon formats.

Other media suggested for delivering continence information included:

- articles in newspapers, particularly local community papers and magazines;
- arranging visiting speakers (eg continence advisors) at women’s groups and clubs such as senior citizens clubs, bowling clubs, Lions and Rotary;
- conduct continence awareness weeks and events; and
- arrange free community meetings with continence nurses and specialists in attendance.

Peak bodies and advocacy groups suggested a number of additional pathways for the distribution of continence information, including:

- continence displays;
- product representatives offering home visits for personal fittings and samples to try;
- organisation newsletters;
- state Community Information Services information helplines;
- spina bifida clinics in large hospitals;
- community service sector organisations;
- pharmacies;
- community health services and womens and mens health services;
- community nurses;
- support and self help groups;
• mailouts; and
• distribution through the aged care industry.

“Advertising awareness programs on TV of Freecall numbers for advice or where your local clinic is.” (Peak Body/Advocacy Group questionnaire respondent)

Several peak bodies and advocacy agencies noted their own roles in distributing information to consumers and carers and suggested the inclusion of continence information in the information kits and packages that they distribute.

An important point made by several stakeholders was that a range of media and distribution channels should be used in order to reach the wide cross-section of people needing continence information and assistance.

Local information initiatives were also recommended:

“Funding should be available to support local continence management strategies, such as funding information sessions, pamphlets on how certain diagnoses can affect continence etc.” (Peak Body/Advocacy Group questionnaire respondent)

Primary Care Partnerships were suggested as a means of information dissemination in Victoria. These PCPs have been established for all local areas in Victoria with the aim of improving access to services and sharing of assessment information. The PCP involves a range of health and community providers including HACC providers, community health services, ACATs, and the Royal District Nursing Service (RDNS).

Another focus group recommended the use of carer support groups with the use of teleconferencing and the inclusion of dedicated sessions on continence issues.

Several respondents warned that a single one-off burst of information for consumers would not be sufficient and that an ongoing and multi-faceted information campaign is required.

“Information is only relevant when you want it. Therefore continence information has to be omnipresent.” (Consumer focus group participant)
6.2.2 The Best Media for Continence Information

Respondents to the Health and Community Workers questionnaire were asked what are the best media for providing continence information to the people they assess or treat.

The most frequently suggested media were pamphlets, television advertising and radio, in that order. The advantages mentioned for pamphlets, were that it was something that the service provider could give the client to read. Television advertising was acknowledged to be expensive (although the possibility of community service announcements was suggested by one respondent). However, it was considered that television would reach a much larger audience than other media. Radio and talk back radio programs were suggested for similar reasons, with the added advantage of access to information for those with literacy problems and in the case of multicultural radio, people who speak languages other than English.

The same question asked of specialist continence practitioners elicited similar responses, with the additional suggestions of:

- internet websites (including a suggestion for a website set up by Government and identifying services assessed as ‘centres of excellence’);
- open days; and
- displays at local community functions, eg field days.

One consumer requested that pamphlets explaining incontinence be more explicit and detailed. Another suggested that pamphlets be on public display “where they can be seen without having to ask for them”. Yet another consumer said they would probably not pick up a pamphlet about incontinence in a public place – consistent with a suggestion from the focus groups that pamphlets be provided in public toilets, where people could take one with some degree of privacy.

Several respondents suggested a telephone advice line or 1800 helpline which might indicate that they are not aware of the existing Continence Helpline. Some of the participants in our telephone interviews liked the idea of telephone advice, saying that they felt less shy about discussing their problems anonymously in this way, even when the listener was the opposite gender.

6.2.3 Alternative Formats

When peak bodies and advocacy groups were asked if the people that their organisation represented were likely to require alternative formats for continence information (such as translation in another language, large print, audiotape, etc), 83% (19 respondents) said yes, 9% (2) responded no, and 9% (2) were unsure. The alternative formats suggested included:

- other languages, including Compic (a symbol language used by some people with severe physical disabilities who cannot use speech);
- large print;
• audiotape;
• videotape;
• telephone information;
• pictures of products;
• simple instructions for people with cognitive impairment; and
• electronic versions on computer disk.

6.2.4 Preventative Information

The link between continence problems and childbirth was also recognized by stakeholders. One suggestion in this respect was improving ante-natal and post-natal education regarding potential continence problems and strategies for prevention and treatment. Service providers noted that providing education and information to new mothers is a challenging task given their intense focus on the new baby. Specific strategies suggested were:

• focus additional attention on the issue about 6 weeks after the birth of the baby;
• raise the issue at the 6 week post-natal check; and
• involve relevant allied health professionals in the education and follow up.

Preventative and proactive initiatives are also required for men, for example:

• general information about incontinence (urinary and faecal) in men;
• awareness of the symptoms associated with continence problems and the changes in urinary function associated with ageing;
• when and how to seek assessment and advice;
• management of minor incontinence problems (for example, post void dribble); and
• avoidance of aggravating factors, such as alcohol and caffeine.

One focus group suggested that men should be encouraged to have regular health checks involving prostate checks, continence problems etc, in a similar approach to the regular screening of women.

Several groups suggested that public education about continence problems needs to start at a young age through the school education system. It was further suggested that teachers and child care workers should be educated about the fundamentals of good bladder and bowel habits so that these behaviours are reinforced for children from an early age.

Other preventative information strategies suggested were:

• Education of parents and teachers about faecal incontinence and enuresis.
• Include preventative education in secondary school health curriculum.
• Post-natal education videos.
• Distribution of pamphlets and promotional material through Centrelink, gyms, fitness centres, sporting clubs, etc.
• Provision of more translation services and production of pamphlets in more languages.
• Provision of information for women at or beyond menopause through menopause groups, senior citizens groups, women’s magazines and shopping centres.
• Promotion of continence information in the workplace.

6.3 Information for Indigenous Communities

Education about incontinence for Aboriginal communities was the subject of a range of suggestions and comments from the stakeholders consulted for this project.

Stakeholders considered it important that continence awareness and education for Aboriginal and Torres Strait Islander people be provided by the appropriate people, in the right location, using culturally appropriate materials and using an approach that encourages the active participation (action learning) of those attending. For best results, continence education should be integrated into general health promotion activities (such as ‘Healthy Ageing’ days) and a lunch or other social activities should be included to encourage people to attend.

The language used in training and information materials for Aboriginal communities must also be appropriate. One service provider focus group suggested that materials designed to be culturally appropriate that use English language may be appropriate only for urban Aboriginal communities. This group also commented that some existing drafts were “too European” and recommended that such materials be developed by and with local communities.

Another group recommended the use of culturally appropriate flip-books and similar materials by Aboriginal health workers to explain incontinence to Aboriginal people.

Carers NSW expressed concern about the lack of Aboriginal-specific resources on incontinence available for Aboriginal carers and suggested that such resources should have the following features:

• written to cater for a lower level of literacy than found among white communities;
• using colours and designs that are ‘Aboriginal-friendly’;
• more culturally appropriate (ie using more pictures); and
• visual resources (such as a short video) may be more appropriate than written materials.

The Aboriginal Development Officer for Carers NSW stated that training and services for Aboriginal carers must be provided in their local communities, as many Aboriginal carers are hesitant or unable to go to larger towns and cities. They suggested it would be useful
if locally-based Aboriginal incontinence advisors (with links to the local communities that they serve) were employed under the National Continence Management Strategy.

*Carers NSW* also referred to a network of Aboriginal Health Workers and Aboriginal Health Education Officers based at Aboriginal Medical Services and Community Health Centres across NSW, who could be trained to deliver information on continence issues to local Aboriginal communities. Other non health-specific Aboriginal organisations, such as Aboriginal Land Councils and Aboriginal housing corporations could also be used to distribute information.

### 6.3.1 Strategies for Increasing Awareness

Strategies for increasing continence awareness amongst Aboriginal and Torres Strait Islander communities were also discussed. Strategies suggested by stakeholders were:

- Continence needs to be promoted through a range of health network agendas at national and local levels.
- The use of local networks (involving health workers, HACC workers, GPs and community workers) is very important in promoting continence issues and providing a coordinated response to continence problems.
- Culturally relevant material needs to be used.
- Importance of learning style should be recognized and an action learning approach used where possible.
- Working on a one-to-one basis with the carer and recognising the importance of word of mouth are valuable strategies.
- Health workers should find out why the person is incontinent, talk with carers, show them the products. Other people will then find out about this and ask for the same.
- It is important for Aboriginal health workers to have a team of other workers eg specialist physiotherapists and continence advisors to access.
- Follow up of continence information and treatment is important. In remote areas community health, Royal Flying Doctor Service or other visiting health services could be enlisted to assist with follow-up.

Further suggestions for presenting continence information to Aboriginal people were:

- Recognise that talking about these things may take a bit longer with Aboriginal people.
- Be sure to select the right location to give continence information.
- Continence promotion should be localised and integrated with other health promotion and education ie putting continence in a *good health* context.
- Know your audience and know your information.
- Know what resources are available and guide people to these resources.
• Use peer education in Aboriginal communities ie involve community members in the presentation of continence information and follow up activities.
• Importance of the way information about incontinence is presented (eg the use of ice breakers to encourage discussion).
• Continence education for women should start around the birth of their first baby eg the *Strong Women - Strong Babies* program.

The use of the Continence Helpline by Aboriginal and Torres Strait Islander people was discussed with some stakeholders. Access to telephones was identified as a barrier to using such a service for many people living in remote Aboriginal communities. Even where a telephone is available, ‘dial out’ access may be restricted. Some stakeholders felt that even if an Aboriginal worker was based at the Helpline, the service would still not be used by many Aboriginal people.

### 6.3.2 Getting Continence on the Agenda

The HACC Aboriginal and Torres Strait Islander Reference Group Continence Sub-Committee were keen to get continence on the Aboriginal and broader health agendas and made the following suggestions:

• This is a broader issue that needs to be raised with Office of Aboriginal and Torres Strait Islander (OATSIH), Royal College of General Practitioners (RACGP), National Aboriginal Community Controlled Health Organisation (NACCHO), etc.
• Continence needs to be on the agenda in a wide number of forums and organisations.
• Need an information kit for people to present to the various networks.
• We need to take an active role in educating doctors and others.
• Need groups or networks where doctors and other health workers can get to know each other and share information eg there is a network in the western region of Adelaide.
• Need examples of good networking.
• Need a strategy for networks to give information back to the National Continence Management Strategy.

### 6.3.3 Good Ideas that Work Well

We received a number of suggestions of ideas and approaches that had worked well in providing continence information and services to Aboriginal communities:

• The Aboriginal Medical Service runs men’s health programs in the Kimberley.
• Continence issues included in Healthy Ageing days. In Victoria, they have ‘Well Person’s’ check days.
• A Carer Respite centre gave out continence information and had a display of continence products.
• The Independent Living Centre in South Australia uses a travelling caravan with samples of products and equipment to visit remote Aboriginal communities. (Their Queensland counterpart does the same)
• A Continence Nurse works with Aboriginal Health Workers, HACC workers and Aboriginal people in the Alice Springs area.
• Meetings of GPs and Aboriginal Health Workers occur in one region - this is supported by Congress.
• Rural Health Team and Community Options in Victoria organise lunches and information sessions for the local elders.
• HACC networks can be used to spread information.
• There is a Council of Aboriginal Elders in South Australia (with representatives from 16 regions) and an ATSIC Women’s Group that can be used to distribute information.
• Providing advocates to accompany Aboriginal people to doctor’s appointments assists discussion and understanding of sensitive issues like incontinence.

6.4 Information for Ethnic Communities

Limited access by ethnic communities to continence information in a format that they can understand was an issue repeatedly raised in the focus groups and other consultations that we conducted.

Consumers and carers stressed that continence information needs to be available in other languages. It was suggested that multilingual fact sheets be available for download from a continence website, avoiding the need for agencies to keep stocks of brochures for all language groups.

With respect to carers from a non-English speaking background, lack of information on incontinence in languages other than English is a barrier to accessing information, services and treatment. (Peak Body/Advocacy Group Questionnaire respondent)

“The lack of multilingual information, interpreters and bilingual health professionals makes it much more difficult for carers/care recipients with limited English language proficiency to raise the problems experienced. Given the sensitivity of the issue generally and the particular meaning incontinence may carry in the family’s own culture, this becomes a significant barrier to reporting.” (Submission from the Carers’ Association of Victoria)

Language barriers were considered to result in:

• lack of knowledge about what continence services and treatments are available;
• lack of knowledge that specially trained health workers such as continence nurses and women’s health physiotherapists exist and what they can offer;
• lack of encouragement for other language groups to seek help with their continence problems; and
• difficulties in accessing schemes for continence aids and equipment and language difficulties in ordering supplies.

It was suggested that the development of continence information for other language groups requires involvement of the communities for whom the information is being prepared and that multicultural health workers should also be consulted.

It was recommended that information be easy to read and understand, kept up to date and strong on visual content eg posters.

Some of the challenges in describing incontinence in other languages were also discussed for example, is there a word for incontinence in all languages?

Poor access to product information for people who do not read English was also described:
• people who can’t read English can’t read the product pamphlets;
• translations may not help (for example if the person is illiterate even in their own language or the language used is too complex);
• people may need direct advice and explanation and are unable to access this;
• they may not be able to get to or find the product supplier; and
• they may have to rely on ethnic workers to obtain continence products for them.

Carers NSW wrote that, as far as they were aware, information on incontinence is available in only four languages other than English. However, there are about 133 different language groups in NSW (Australian Bureau of Statistics 1996 Census data).

Although this organisation acknowledged that it is probably unrealistic to provide translations for all these groups, they recommended that information on incontinence be translated into a much wider group of languages - particularly for language groups whose populations are ageing rapidly.

The Carers NSW multicultural development officer suggested that an active outreach program within communities of cultural and linguistic diversity would be the best way to deliver information on incontinence to carers in these communities. One method of doing this would be for Continence Advisors based in Community Health Centres to work with local Migrant Resource Centres to access local migrant communities. Another suggestion was for specialist Migrant Outreach Workers to be employed under the National Continence Management Strategy.

Carers NSW reported that other work the organisation had been involved in had demonstrated that outreach among migrant communities is needed to effectively deliver information to them.
6.4.1 Use of Interpreters and Translations

One of the service provider focus groups raised concerns about the use of inappropriate or untrained interpreters. For example:

- situations where the interpreters are not appropriate (for example, it can be “disastrous” to use family members as interpreters in continence related situations); and

- terminology issues, such as being able to correctly translate the clinical information about incontinence into colloquial language.

It was also noted that some health workers are reluctant to use interpreters for reasons such as “it takes too long”, “the arrangements are too complex” and “it is too much trouble”. This focus group emphasized the importance of health professionals using professional interpreters and suggested the Telephone Interpreter Service (TIS) as an appropriate option.

“GPs have to prepare an appropriate environment, arrange an interpreter, etc. The process has to be carefully thought out for such a sensitive issue.” (Service provider focus group participants)

Problems were identified with availability of interpreters, particularly to cover the range of language groups present in Australia. One Northern Territory service provider noted that there are 80 different Aboriginal dialects in the Top End alone without counting ethnic languages and English may be a second or third language for some people.

Stakeholders made some specific suggestions in respect of interpreting and translation services:

- Protocols should be developed for the use of appropriate interpreters.
- More resources should be provided for interpreting services.
- There should be a quality control system for translated information/documents.
- Family members should not be used for interpreting - especially for discussions involving continence problems.

Specific languages requested for translations of continence information were:

- Polish
- Greek
- Chinese
- Italian

all requested by an advocacy organisation located in Tasmania;

- Italian
- Greek
- Vietnamese
- Mandarin

requested by a disability peak body in Victoria; and
One stakeholder commented that the major language groups are reasonably well catered for but not smaller groups (particularly recently arrived migrants) and another noted a lack of appropriate information and language translations for refugee groups.

Focus group participants provided a note of caution that all the written translations in the world will not assist those who are not literate including those who are not literate in their own language – a not uncommon situation for older people. These people may require other information strategies such as verbal explanations and pictorial materials such as posters and videos.

It was also suggested that translations may not cater for different dialects and levels of language and that translations need to be written in conversational language, not technical/clinical language.

### 6.4.2 Telephone Helpline

The use of telephone helplines (such as the CFA Continence Helpline) by people from ethnic communities was discussed by focus group participants. A number of barriers were identified:

- many consumers and service providers don’t know that the Helpline is available;
- access to interpreters is limited;
- “a lot of people can’t get their message across and give up”;
- “they don’t like talking or listening to an answering machine”; and
- use of the telephone as an information source may present a barrier if the person is not able to talk with someone in their own language.

Some stakeholders doubted that their ethnic consumers would use a telephone helpline.

“I don’t think that a telephone advice line would help my ethnic population, probably pamphlets, education material via ethnic unit and community service groups.” (Health and Community Worker questionnaire respondent)

Marketing of the Continence Helpline to health and community workers in ethnic communities was recommended by one of the service provider focus groups. It was also suggested that the Continence Helpline needs to link with face to face multicultural
services and ethnic communities and to work through ethnic community groups. It was thought that this approach may be more effective than directing people individually to a helpline. It was acknowledged, however, that such an approach would require more time and money and would need to be supported by a community development philosophy.

6.4.3 Continence Education and Awareness for Ethnic Communities

Stakeholders were concerned that ethnic communities should be included in any national or local community education and awareness campaigns. The multicultural groups that we consulted produced a long list of suggestions in this respect. For example:

- Need for a nationally coordinated and diverse media approach (eg through radio - local and SBS, newspapers, community groups, television, women’s magazines, Internet, GP’s rooms, videos, CD-Roms).
- Working with ethnic groups to establish the best means of communication.
- Additional resources for interpreting services.
- Inclusion of continence issues in other health and well-being events, strategies etc.
- Use of local (vs statewide or national) resources and awareness raising activities.
- Use of the Internet as a distribution network eg for multicultural continence information resources.
- Information in other languages in Aged Care Pension News.
- Church groups, pensioner groups.
- Local coffee shop eg posters.
- Stickers in men’s/women’s toilets.
- Multicultural newspapers and magazines.
- Information in other languages placed in ethnic community GP surgeries and pharmacies and specialist waiting rooms.

One carer organisation considered that the use of the ethnic media (radio, newspapers, TV) would be more effective in reaching ethnic communities than mainstream media.

6.5 Community Education

Most stakeholders consulted for this project have recommended a community education campaign to:

- raise community awareness of continence issues and treatment options (ie awareness that ‘something can be done’);
- increase community acceptance of incontinence (removing the ‘taboo’);
- increase peoples’ comfort in talking about their continence problems with health workers; and
• promote prevention, treatment and rehabilitation options (to balance the commercial promotion of pads and products).

Marketing continence messages in a similar way to the campaigns for Breastscreen and Pap smears has been suggested. Another suggestion was an ongoing media campaign with scenarios involving high profile and/or credible personalities and situations that people can relate to.

The importance of using a range of different media and of having both short and long term promotional strategies has been noted.

Key continence promotion messages suggested for a community education campaign are:

• ‘Incontinence is a common problem – you are not alone’
• ‘Incontinence is not an inevitable part of growing old or giving birth’
• ‘You don’t have to put up with incontinence – Something can be done’
• ‘A range of prevention, treatment and management options are available’
• ‘Incontinence may not always be cured, but it can be helped’
• ‘It’s OK to talk about continence problems with your GP or other health worker’
• ‘Incontinence might be an embarrassing problem but don’t let that stop you getting help’
• ‘Take the shame out of incontinence’
• ‘Minimize the stigma’
• ‘Dispel the myths about incontinence’
• ‘Demystify incontinence’
• ‘Incontinence is not just a women’s problem’

One cautionary point was made:
Any promotional campaign needs to be coordinated with service providers (including helplines, doctors, continence clinics, community health nurses, etc). Service providers need to be ready to cope with any increased demand resulting from a promotional campaign and service provider attitudes, skills and response to consumer approaches need to match the expectations created by the promotional campaign. (The National Continence Helpline observes a noticeable increase in the volume of calls after articles appear in a magazine or newspaper.)
7.0 Training Requirements for Service Providers

7.1 Introduction

As is evident from the review of the research literature and the consultations undertaken for this project, health practitioners and other continence service providers play an integral role in the reporting, assessment and treatment of continence problems. Appropriate training for the key players in this continence service system is an important precursor to a positive response and appropriate advice for people with continence problems.

Providing access to appropriate training is also an important strategy in recruiting more health workers to the field of continence practitioners. Whether health workers choose to add basic continence assessment, management and referral to their general skills or to specialize in this area, the pool of health practitioners who are competent and confident to discuss the subject of continence problems with their patients/clients and to respond appropriately to these problems, should be increased through the provision of training.

7.2 Unmet Information and Training Needs

Respondents to our service provider questionnaires were asked if they or their colleagues had any unmet information or training needs in respect of incontinence assessment, management, treatment or prevention. The responses are summarized in the following table. As shown in the table, the majority (56%) of all questionnaire respondents indicated a need for further information or training and this need was identified for the majority of respondents in all three of the questionnaire groups.

<table>
<thead>
<tr>
<th>Service provider need for information and training</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACAT Members (n=102)</td>
<td>55</td>
<td>34</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>(54%)</td>
<td>(33%)</td>
<td>(13%)</td>
</tr>
<tr>
<td>Health &amp; Community Workers (n=63)</td>
<td>38</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>(60%)</td>
<td>(24%)</td>
<td>(16%)</td>
</tr>
<tr>
<td>Specialist Continence Practitioners (n=14)</td>
<td>8</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(57%)</td>
<td>(36%)</td>
<td>(7%)</td>
</tr>
<tr>
<td>TOTAL (n=179)</td>
<td>101</td>
<td>54</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>(56%)</td>
<td>(30%)</td>
<td>(15%)</td>
</tr>
</tbody>
</table>

Note: Percentages rounded to nearest whole number so the totals do not add up to 100%

Many respondents commented that they would benefit from an update of their knowledge and skills in this area. Written comments from Health and Community Workers suggested the need for training on continence assessment and management and information about the services and supports available.
Some GPs reported that they had received no formal training in this area and others suggested this would be a good topic for Continuing Medical Education (CME).

Additional training requested by members of ACAT teams included the causes, treatment, support networks and financial assistance available to people with continence problems. One ACAT member requested information to differentiate which continence problems are more amenable to intervention and which require management.

“We need to be able to offer our clients more help than incontinence pads. Need information on where help is available. How can help be accessed?” (Health and Community Worker questionnaire respondent)

Some specific training requests were made, such as education on the effects of medications, when to refer and to whom, new products and appliances, and supra pubic catheterization.

Some nurses in rural and remote areas described the difficulties they faced keeping their knowledge and skills up to date in an isolated environment.

“I feel that as a country Continence Nurse Advisor I am isolated from the current trends and peer support. I would like to see a country CNA group formed to help overcome these issues.” (Specialist Continence Practitioner questionnaire respondent)

Consumer and carer representatives had strong views about the need for training of health and community service providers regarding continence problems. General Practitioners were a particular focus of attention.

“GPs are the first port of call. They need to raise continence issues. They need to give an appropriate response. They need to know about the Helpline and other services – GPs need education.” (Consumer focus group participant)

“Very few GPs or community nurses know who the appropriate specialists are in their local area. Very few of them are aware of how MS affects the bladder. Even fewer ask the patient ‘Do you ever wet your pants/have trouble getting to the toilet in time?’ etc This leads to under reporting of the problem, as patients are not given permission to talk about it. Local health providers need training to ask these questions routinely, and then refer on to appropriate specialists.” (Peak Body/Advocacy Group Questionnaire respondent)

“GPs need to be better informed. They need to be aware that they can make a real difference.” (Consumer participating in telephone interview)
One peak body representing people with Multiple Sclerosis suggested that specialists need more diagnosis-specific information about the impact of other symptoms (e.g., leg spasms and reduced hand function) on continence management.

Participants in the service provider focus groups were asked what information and training is needed by health professionals in respect of the prevention, assessment and treatment of urinary and faecal incontinence. The responses included:

- education for allied health professionals in incontinence and its effect on people’s quality of life and where to refer people for more information;
- compulsory units in nursing, medical, allied health and Aboriginal Health worker training curricula;
- more culturally appropriate training for Aboriginal Health workers and ethnic workers;
- ongoing education such as refresher courses and work days for existing health professionals;
- training for GPs through the RACGP or Divisions of General Practice;
- basic training on what is normal, what services are available and where to access these, when to refer, and the effect of diseases on continence;
- training with a positive focus;
- training to raise the profile of nurses and GPs roles in managing incontinence;
- training in ‘cue questions’ for continence;
- communication and counselling skills training; and
- awareness of risk factors.

"Training is needed. For example, one client had huge continence problems but these were missed despite hospital and ACAT assessments. They ended up in a nursing home.” (Focus group participant)

"Health professionals are not recognizing incontinence as a sign of something going seriously wrong. Doctors need to recognize the importance of looking for more significant causes. The knowledge is not there.” (Focus group participant)

Specialist continence practitioners were more focused on the need for training updates regarding new products, procedures and treatments. One urologist suggested a need for greater awareness of the continence services that have developed in the community and suggested that greater liaison between urologists and continence advisors may be helpful.

The information and training needs of domiciliary, home help and personal care workers, providing care and support to people with continence problems were also considered important.
“Home help workers are likely to encounter the practical effects of incontinence. Home carers get to know people very well and get to know these (incontinence) issues – they can then pass this information on to the assessment team. It is important to get continence information to this group. Home carers are often from similar socio-economic and cultural backgrounds to the people they are caring for.” (Carer focus group participants)

It was suggested that a continence module should be an essential part of the basic training for HACC workers, community care workers, and community nurses (not an elective or optional subject). One group suggested the use of standard modules across the various training courses and training packages at three different levels eg basic awareness, more detailed information and advanced, specialist training.

Concerns were raised by some focus group participants and questionnaire respondents about the management of incontinence in hospitals and residential aged care facilities (hostels and nursing homes). A key issue was the reported tendency to “pad up” the incontinent person and use other containment aids, rather than ensuring appropriate assessment, diagnosis and treatment/rehabilitation of the problem.

Training for staff of respite care facilities was also recommended by one carers’ organisation who suggested that carers and care recipients are discouraged from using respite services where incontinence is not well-managed. A case example of a young girl with multiple disabilities being left wet and soiled for a long period in a respite care facility was described. This organisation identified a need for:

- information and education of respite care service staff regarding incontinence and its management;
- the adoption of organizational practices which minimize the problem;
- individualised management of people in respite and permanent care; and
- listening to and adopting or adapting the strategies developed by the carer or family to manage the person’s incontinence.

7.2.1 Resourcing Training Programs

In respect of training for GPs, many service providers participating in this project’s consultations recommended working through the Divisions of General Practice to update GP skills and knowledge in this area.

One Division of General Practice (Townsville) reported they were already preparing an initiative to educate local GPs about conservative management of female incontinence.

Other national initiatives for general practice may provide a means of delivery of information about incontinence, updating clinical skills and generating demand for continence training.
The new Enhanced Primary Care Medicare Benefit Schedule items provide for annual Medicare-rebated health assessments for people aged 75 years and over living in the general community and those aged 55 years and over in Aboriginal and Torres Strait Islander communities. The Health Assessment proforma provided to GPs for this program includes an assessment item for continence. This item asks about:

- Leaking urine? (never/sometimes/often)
- Is this related to coughing or sneezing? (Y/N)
- Faecal soiling/change of bowel habit (Never/sometimes/often)

The guidelines for these Health Assessments (RACGP, 2000) include basic information on continence assessment and reference to further sources of information, including the National Continence Helpline. Mention is made of the tendency of patients not to report incontinence and the importance of direct questioning in this area. Although these guidelines provide the fundamentals of what to assess (eg symptoms, effect on quality of life, abdominal examination), the finer details of how to assess, when to refer, etc are dependent on the GP’s previous experience and training in this area.

Training for state/territory-funded hospital and health service staff appears to be limited by resource constraints. One service provider focus group expressed concerns that training was not seen as a priority and gave the example of hospitals not releasing staff to attend continence training. Other respondents noted difficulties in accessing training opportunities due to:

- the cost of training courses;
- lack of resources for staff replacement; and
- in rural and remote areas, the travel distance required.

Service providers in the Northern Territory reported time and funding restrictions for continence training. For example, non-Territory Health Service health clinics in remote areas have to pay for training from THS. Some remote communities can afford this due to income from mining rights, whereas others do not have this source of funding.

Some ACATs wrote that they organized their own inservice training and education sessions, although the availability of continence specialists to help deliver this training was a problem.

Local continence networking and information sharing activities can be very useful and cost little. A community nurse reported:

“In our area we meet 3 monthly with all associated groups re ‘incontinence issues’ at the local Community Health Centre. This has proved to be invaluable at sharing information, gaining updates and organizing education needs for staff and clients.”
### 7.2.2 Existing Training Programs

Registered Nurses in most states can access specialist postgraduate courses to commence practice as Continence Nurse Advisors. Shorter programs are also available for enrolled nurses and personal care/community care workers.

<table>
<thead>
<tr>
<th>State/Territory</th>
<th>Post Graduate Courses for RNs Enabling Practice as CNAs</th>
<th>Other Training and Awareness Courses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Queensland</td>
<td>Postgraduate continence care course delivered by Blue Care Nursing in collaboration with the Australian Catholic University</td>
<td>Blue Care Continence Promotion course – 2 days covering simple assessment and management strategies. One day course for health workers, respite workers, etc. Two day Continence Promotion course provided by Cairns Base Hospital.</td>
</tr>
<tr>
<td>South Australia</td>
<td>Flinders University provides Grad Cert in Health (Continence) – a part-time year long external course for RNs</td>
<td>Flinders University in conjunction with Repatriation General Hospital offers short courses for RNs and ENs. RDNS provides a Continence Promotion Course by distance education (RDNS Certificate qualification). Average duration 15 weeks. Provides option of 6 unit credit status with the post graduate programs in Nursing and Midwifery at Flinders University.</td>
</tr>
<tr>
<td>Western Australia</td>
<td>Hollywood Hospital in conjunction with Curtin University provides a 4 week full-time Continence Nurse Consultants course. Nationally recognized certificate of completion and graduates eligible to apply for credit points in tertiary study. Prerequisites: RGN or RMHN with 12 months post-registration experience.</td>
<td>Inservice study days held at major hospitals and through the CFA office at Hollywood Hospital</td>
</tr>
<tr>
<td>Victoria</td>
<td>LaTrobe University offers a continence subject as part of Post Grad Dip Nursing (eg Women’s Health or Gerontology Nursing). This subject is one semester by distance education, average duration 13-15 weeks. Later this year, LaTrobe will include a continence subject in a Post Grad Cert in Urological Nursing. HealthLinks (part of RDNS) offers Grad Cert in Advanced Clinical Nursing Practice (Continence Promotion). Duration 1 semester by distance education</td>
<td>Mayfield Education Centre offers short courses (eg 3 days) for RNs, ENs and personal care attendants. Sanicare offers 2 day course in continence management and promotion</td>
</tr>
</tbody>
</table>

The postgraduate courses listed in the centre column of the table above enable Registered Nurses to commence practice as Continence Nurse Advisors and can also contribute to other graduate qualifications. The other training and awareness courses enable nurses and other health and personal care workers to develop their continence skills but do not generally provide credit to a formal continence qualification.
Course fees are charged for the university-based courses and so participants must be either self-funding or funded by their employer. Most of the nurses completing these courses do so externally (ie by distance learning/correspondence).

In terms of the shortage of Continence Nurse Advisors referred to by many stakeholders during this project’s consultations, the problem does not appear to be a shortage of training options (given that the university-based courses are generally available externally) but rather a shortage of registered nurses choosing to complete this training and to continue practice in this specialty area, particularly in rural and remote regions of Australia. It may be useful to conduct an audit of Continence Nurse Advisors throughout Australia to determine if and where they are practicing and thereby determine the geographic areas with no access to continence nursing services.

It appears that some training and awareness sessions are being provided through Divisions of General Practice, but these occur on an ad-hoc basis and are driven by the individual divisions.

Post graduate programs are available for physiotherapists in the area of women’s health. For example, Melbourne University offers postgraduate continence training for physiotherapists.

The Royal Australian and New Zealand College of Obstetrics and Gynaecology has a formal training program run by its Urogynaecology Sub-committee for the subspecialty qualification in Urogynaecology. The training program is three years in duration and involves research and clinical training in recognized training positions. Candidates must complete a thesis in their research field and pass written and clinical examinations. This training is carried out after completion of training in the specialty of Obstetrics and Gynaecology.

From this brief review of existing training programs for health practitioners it would appear that the most important points of first contact for people with continence problems, general practitioners, are the group least endowed with formal continence training opportunities.

7.3 Training for Aboriginal Health Workers

Training of Aboriginal health workers in the preliminary identification, assessment, referral and management of incontinence was seen as a major pathway for improving the management and treatment of incontinence amongst Aboriginal and Torres Strait Islander communities. It was suggested that Aboriginal health workers need increased awareness and knowledge of incontinence, need to see continence as a priority issue and need continence training as part of their basic training curriculum.

Key topics for inclusion in continence training curricula for Aboriginal health workers and other health, aged care and community workers providing services to Aboriginal and Torres Strait Islander communities were suggested:
understanding of the concept of ‘incontinence’ and what incontinence is;
what treatment and services are available;
where to refer people for specialist help;
how to prevent continence problems;
what resources are available;
how to manage time and resource needs;
how to include continence in other programs;
training in cultural issues;
training in the use of local community, family members and local doctor; and
strategies for delivering services in remote communities.

In terms of the mode of delivery of training to Aboriginal health workers, stakeholders suggested:
• course designers and training providers need to understand how Aboriginal people learn best ie through active participation; and
• a range of media (such as audiotape and videotape) should be used for training.

In addition to basic training, Aboriginal health workers need access to specialist continence practitioners (of both genders if possible) who can provide them with advice and information and assist with assessment and treatment of people with continence problems.

Participants in one service providers’ focus group reported difficulties in getting Aboriginal health workers released to attend training courses but noted that when they were able to attend, they found the training to be a very positive experience. Time and funding were suggested as major barriers to the provision of continence training for existing Aboriginal health workers.

7.4 Cultural Awareness Training

Training in the specific needs and issues of other cultural groups is also needed.

Stakeholders noted a lack of undergraduate education, knowledge base and enthusiasm for continence education of health professionals accessed by ethnic communities. It was suggested there is a need for:
• information on incontinence and treatment options for the range of health and allied health professionals who provide services to ethnic communities (including GPs, nurses, social workers, occupational therapists, physiotherapists, migrant resource centre workers, and welfare centre staff); and
• cross cultural training of health and other workers (including training in the use of interpreters).

One carers’ organisation suggested that community workers need information and training about:
• “How incontinence is viewed by different age cohorts and different cultural groups in Australia (understanding different attitudes and taboos in regards to incontinence”;
• “The impacts incontinence can have on the person concerned, their carer and other family members (especially re stigma/ostracism, social isolation, various financial impacts, the physical care burden eg laundry and personal care).”

7.5 Appropriate Training Strategies
Health and community workers, specialist continence practitioners and other service providers were asked to suggest the best means of providing themselves and their colleagues with information and training. Their suggestions were:
• use a range of mediums from articles in newsletters to formal training sessions;
• use forums such as lectures, CME events, educational dinners, workshops and seminars (night or half day);
• utilize local Divisions of General Practice to facilitate the training;
• provide incentives for postgraduate education eg training points;
• develop distance education and multi-media packages;
• use videoconference sessions through the College of Rural Medicine;
• develop brief assessment and treatment guides;
• provide hands-on clinical support and advice;
• provide inservice training;
• encourage incontinence education as part of professional development for all health professionals;
• education through professional organisations such as the Nursing for Continence Interest Group and Continence Foundation of Australia;
• use experiential learning eg working alongside an experienced continence nurse or placement in a continence clinic;
• provide preceptorship for self-directed packages;
• self-directed learning options to support workshops and other group learning processes;
• use case studies; and
• articles in professional journals.
An important request was for some degree of consistency in continence assessment and treatment protocols and in training curricula across all health practitioner groups.

“Make it consistent – Have some uniformity in investigation, assessment, treatment observed by all health professionals involved in dealing with incontinence.” (Health and Community Worker questionnaire respondent)
8.0 Stakeholder Expectations of the National Continence Management Strategy and the Service Sector

Health and community workers and specialist continence practitioners responding to our questionnaires were asked if they were aware of the National Continence Management Strategy. Peak bodies and advocacy groups were asked the same question. The levels of awareness across the three questionnaire groups are summarized in the table below.

<table>
<thead>
<tr>
<th>Awareness of the National Continence Management Strategy</th>
<th>Health &amp; Community Workers (n=47)</th>
<th>Specialist Continence Practitioners (n=15)</th>
<th>Peak Bodies and Advocacy Groups (n=23)</th>
<th>TOTAL across all groups (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Yes, familiar with the Strategy, its objectives and initiatives</td>
<td>3 (6%)</td>
<td>10 (67%)</td>
<td>15 (65%)</td>
<td>28 (33%)</td>
</tr>
<tr>
<td>B. Have heard of the Strategy but do not know any details</td>
<td>22 (47%)</td>
<td>4 (27%)</td>
<td>5 (22%)</td>
<td>31 (36%)</td>
</tr>
<tr>
<td>C. Have not known of the Strategy until now</td>
<td>22 (47%)</td>
<td>1 (7%)</td>
<td>3 (13%)</td>
<td>26 (31%)</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The Health and Community Workers group (which largely comprised community nurses and general practitioners) had the lowest level of awareness with 47% not having known of the Strategy until receiving the questionnaire and accompanying information. The same proportion of this group had heard of the Strategy but did not know any details. Note that 19 (29%) of the total Health and Community Worker questionnaire sample did not respond to this question, suggesting that the level of awareness of this group may have been lower than that indicated by those who did respond.

Not surprisingly, specialist continence practitioners and peak bodies/advocacy groups had a much higher level of awareness with 65% to 67% responding that they were familiar with the Strategy, its objectives and initiatives. Earlier mail outs to key organisations in these two groups, advising them of the first round of consultations and focus groups for this project may have played a role in informing them of the Strategy.

8.1 Consumer and Carer Expectations

Consumers, carers and their peak bodies and advocacy groups were invited to voice their expectations of the National Continence Management Strategy. They responded with a range of expectations and objectives, including:

- Reduce the stigma of incontinence.
- Increase awareness of continence as an issue affecting vast numbers of our population.
• Lead to or help in the development of best practice in continence management.
• Provide future directions and initiatives in the development of an adequate continence management strategy.
• Provide a coordinated response.
• Well managed and accessible services for all people with continence needs.
• Improved treatment and management and access to these.
• Better awareness (amongst GPs and consumers) of the medications and treatments that are available.
• Reduce the cost of incontinence.
• Easier access to assessment and aids at an affordable price for all people with incontinence.
• Assistance commensurate with individual need.
• Clear guidelines for how to advertise incontinence products and information and a central place to access this information from.
• Prevent incontinence from being a major factor in older people needing to move into residential care and from having to move from hostels to nursing home level care.
• Strategies that will be of benefit to people with disabilities and the ageing sector. Not just rhetoric or top heavy administration.
• Increased awareness amongst health care and support workers of continence issues and increased referral to continence advisors.
• Better understanding of incidence and prevalence.
• Expanded knowledge of available continence services.

“While the carer may be aware that some assistance is available, not knowing exactly who to seek help from and how to go about it can prevent many families from getting appropriate treatment and assistance. From a carers’ perspective there is no clear visible pathway to help with incontinence in a system that is complex and poorly co-ordinated – eg differing pathways according to age, condition and various eligibility considerations regarding the particular type of assistance needed.”

(Submission from the Carers Association of Victoria)

8.2 Service Provider Expectations

Service provider questionnaire respondents were invited to describe their expectations of the Strategy. The most frequent expectation (and desire) for the Strategy was an increase in public and health worker awareness of the supports and services available for continence problems. Other expectations included:
• Increase the level of continence in the Australian population through increased awareness and encouragement to seek help.
• Increase public and health professional awareness of, and sensitization to, the issues related to urinary and faecal incontinence.
• Clear and inclusive recommendations for the evaluation and management of incontinence and a sound base of knowledge from which to proceed in a coordinated way to the future.
• Promote the workforce and facilities to manage incontinence.
• Increase the number of continence advisors, particularly outside of the metropolitan area.
• Ensure that the standard of continence care can be levelled statewide and nationally by cross-fertilising information and resources, for equity and efficiency.
• Raise awareness of the need to try conservative treatment approaches first.
• Increased awareness in ethnic communities.
• Make continence aids more accessible and affordable.
• Allow people better access to professional help.
• More resources for us to distribute.
• Have incontinence accepted on the National Health Agenda.

8.3 Stakeholder Suggestions for the National Continence Management Strategy

Service providers suggested the following strategies:
• Community education and raising public awareness
  - breaking down the taboo
  - demystifying the problem
  - minimizing the stigma
  - letting people know they will get a positive response if they report.
• Educating the health sector to encourage reporting, provide appropriate advice and pay more attention to this issue.
• Providing the resources to meet increased demand flowing from community education (including personnel, equipment, accessible services, culturally appropriate services).
• Encouraging service providers to be visible and proactive in promoting their services.

All focus groups recommended the need for a community education campaign as described in section 6.4 of this report.
Most of the stakeholder suggestions for, and expectations of, the National Continence Management Strategy are consistent with the results of broader consultations undertaken for this project, with key themes of:

- community education and awareness;
- improved training and resources for health workers and continence service providers;
- better information for consumers and carers;
- reduced cost for consumers and carers; and
- improved access to appropriate assessment and treatment of continence problems.

The importance of the Strategy in providing a research and information base from which to develop further policy and plan service and funding priorities was also recognized by some stakeholders.
9.0 Conclusions and Recommendations

Our research into the reasons for under-reporting of continence problems and barriers to accessing continence information, services and treatment has identified the following major issues:

- embarrassment, shame and social stigma associated with incontinence presenting a major barrier to the reporting of continence problems for all major Australian cultural groups;
- lack of community awareness and understanding of incontinence and the treatment options, services and supports available, including incorrect perceptions that incontinence is an inevitable result of childbirth and ageing;
- a need for community education and the development of consumer and carer information strategies and resources (including information for indigenous and ethnic communities);
- a need for training and education of health practitioners (particularly general practitioners as a first point of contact), community care workers and residential care staff in the assessment, treatment, management and referral of people with continence problems; and
- a need to more adequately resource the continence service system, particularly in rural and remote areas, including more effective utilization of existing resources.

Our research team considers that there are several key areas where action is required to address the issues of under-reporting of continence problems and barriers to accessing continence services. Key issues and suggested strategies are outlined in Sections 9.1 to 9.8, following. Recommendations and priorities for action are provided in Sections 9.9 and 9.10 respectively. A number of issues raised by stakeholders during the research consultations were determined to be beyond the scope of the National Continence Management Strategy and the ambit of the Commonwealth Department of Health and Aged Care. These issues are documented in Section 9.11.

9.1 Community Education and Awareness

This research project has found that community understanding of, and attitudes towards, incontinence are major contributors to under-reporting of continence problems. The research team has concluded that a national community awareness strategy is needed to improve community awareness of continence problems and the options for managing, treating and preventing incontinence. This need was identified through our consultations with consumers and service providers and was supported by the findings of our review of the research literature.

Such a community awareness strategy should have the following aims:

1. to reduce the taboo, social stigma and embarrassment of incontinence and encourage discussion about continence problems;
2. to increase community knowledge of what incontinence is and what causes it;
3. to increase community awareness of the options available for prevention, treatment and management of incontinence;

4. to increase community awareness of the National Continence Helpline and the national continence website; and

5. to increase the reporting of continence problems to general practitioners, nurses and other health workers.

Both short term and long term promotional strategies should be used.

Stakeholders suggested that a range of media (including television, radio, newspapers, pamphlets and posters) be used to deliver the following key messages to the general community:

- incontinence (leakage of urine or faeces) is a common problem;
- incontinence is not an inevitable result of childbirth or ageing;
- incontinence can be prevented, treated and in many cases cured;
- there are a range of treatments available, including a number of non-surgical options;
- there are supports and services to help carers and consumers manage incontinence;
- people should not allow embarrassment to stop them from getting help;
- people should ask their general practitioner, community health centre or community nursing service for more information; and
- the National Continence Helpline provides free, confidential information from trained Continence Nurse Advisors or people can visit the national continence website.

It was also suggested that a national community awareness strategy be supported with local initiatives, including:

- articles and advertisements in local community newspapers;
- promotions and information displays at community events;
- speakers at community clubs and organisations;
- information resources for specific consumer and carer groups (for example, carers of people with dementia, or people with Multiple Sclerosis);
- dissemination of information through disability, consumer and carer organisations;
- articles and advertisements in ethnic community newspapers and newsletters;
- features and programs on multicultural radio and television;
- information programs in Aboriginal and Torres Strait Islander communities; and
- placement of leaflets, stickers and posters in public and semi-public toilets.
Where possible, these local initiatives should be linked to the national community awareness strategy and where appropriate, should use nationally consistent information and resources (with local adaptations or translations as required) with consistent badging, logo and design.

Our consulting team also considers that it is important to precede the community awareness strategy with a ‘gearing up’ of the health service sector and specialist continence services to respond to the increased demand that would be expected from increased community awareness. This preparation should include:

- advance notice of the campaign to health and community service providers, including all general practitioners, community/district nursing services, community health centres, pharmacists and specialist continence practitioners (through peak bodies and professional bodies if individual notification is not feasible);
- distribution of information kits and assessment/referral/management guidelines to health and community service providers;
- provision of additional continence training sessions through Divisions of General Practice, professional organisations and existing continence training providers; and
- immediately prior to television and radio promotions, distribution of promotional resource materials such as pamphlets and posters to community health outlets including general practice consulting rooms, pharmacies, community health centres and other community information sources such as libraries.

Our research also identified a need for proactive and preventative continence information and education programs including:

- improved ante-natal and post-natal education and follow-up for childbearing women (and additional training and information resources for the health practitioners who generally provide this education);
- information targeted to peri-menopausal women regarding the treatment options available for continence problems they may be experiencing;
- information for men regarding the causes and treatment of male incontinence, management strategies for minor incontinence, awareness of continence-related symptoms that require further assessment, and how to obtain assistance and advice;
- preventative information for parents, teachers and child care workers (such as developing good bladder and bowel habits, how to respond to childhood toileting accidents, and when and where to seek help for bedwetting); and
- inclusion of continence promotion information (for example, good bladder and bowel habits, what causes incontinence, and the importance of a strong pelvic floor) in secondary school health education curricula.
9.2 Information for Consumers and Carers

A community awareness strategy needs to be supported by appropriate, accurate, user-friendly and accessible information for consumers and carers. Service providers consulted for this review reported a lack of appropriate continence information resources and materials for consumers and carers. Our research team has considered the information needs identified by stakeholders and the existing and planned resources in this area. We suggest that the following strategies may assist in improving access to appropriate continence information for consumers and carers.

a) Promote the Australian Directory of Continence Services (currently being developed by the Continence Foundation of Australia) to consumers and carers and how to access directory information through the national Continence Helpline and/or a national continence website.

b) Encourage health practitioners, community services and peak bodies/advocacy groups to obtain and distribute relevant extracts from the Directory of Continence Services (through the Continence Helpline or continence website) to their patients, consumers, and members.

c) Ensure that linkages are in place between the National Continence Helpline and other consumer and carer Helplines and information services (for example those provided by carer organisations, specific disability organisations, and government information services).

d) Design a simple, diagrammatic/pictorial ‘map’ of the continence service system for consumers and carers, showing the key components of this system (ie general practitioners, community nurses, continence nurse advisors, continence clinics, specialist physiotherapists, urologists, urogynaecologists, colo-rectal specialists, geriatricians, Aged Care Assessment teams, dieticians, aids and equipment schemes, National Continence Helpline, national continence website) and a brief statement about the role of each of these service providers. The ‘map’ should be suitable for production as a poster (eg titled ‘Where to get help for continence problems’) and should include spaces for the insertion of local phone numbers. Consideration should also be given to incorporating the map on the national continence website.

e) Work with disability peak bodies to provide continence information resources in accessible formats for their constituents, for example large print, audiotape, plain English, electronic and Compic formats.
9.3 Access to Appropriate Services

This research project examined the barriers to accessing continence services. The most significant barrier identified by consumers, carers and service providers was the availability of continence services. Comments received during our research consultations suggest that many existing continence clinics have limited operating hours, long waiting lists and are located in places that are hard to find or access. A poor level of awareness of the continence services that are available was also reported amongst both consumers and service providers.

It was strongly suggested that the number of practicing continence nurse advisors, particularly in rural and remote areas of Australia needs to be increased and that strategies such as recruitment initiatives and incentives for training, continuing practice and ongoing professional education in this field of nursing should be considered.

The plight of consumers and carers who are housebound and unable to travel to continence clinics, even in urban areas, was also raised. Promoting the use of visiting continence assessment and training services for housebound consumers and carers was suggested.

Some stakeholders also identified a shortage of public physiotherapy services for people with continence services and it was suggested that the availability of such services be reviewed.

9.4 Services in Rural and Remote Areas

Continence services for rural and remote communities were the subject of comment from a number of consumers and service providers. The key issue raised was a lack of continence services in rural and remote areas, with consumers having to travel long distances to access the services of a continence clinic or specialist practitioner such as a continence nurse advisor or physiotherapist specializing in this area. Comments from consumers suggest that many are discouraged from seeking treatment (particularly non-surgical treatments that may require a series of visits to a continence practitioner) by excessive travel requirements.

Another problem reported by several consumers was difficulty in seeking assistance for continence problems from local health practitioners in small communities, where people often have a range of social, business and other contacts with the local doctor or nurse, exacerbating the issues of embarrassment and confidentiality.

Considerations for regional health services in reviewing the availability of continence services in rural and remote areas of Australia, include the capacity of any existing continence services, length of waiting lists and, in areas where no continence services exist, the frequency of visiting services and traveling time to the nearest continence clinic.
In South Australia and Queensland, visits by mobile units providing continence information and displays of continence products to rural and remote communities have been tried, reportedly with some success. Encouraging the use of visiting mobile continence information and assessment units for remote communities and where possible, coordinating these visits with community education initiatives and training of local health workers would seem to be a potentially effective strategy for increasing access to continence services.

9.5 Indigenous Communities

Indigenous communities have particular cultural needs in respect of continence information and services (refer Sections 4.8, 5.3, 6.3 and 7.3 of this report). These needs may occur in remote environments where the provision of even basic health services can be challenging. Despite the impacts on general health, well-being and social inclusion, incontinence may take a low priority against other life needs. A concerted effort is therefore required to raise awareness and understanding of continence problems in indigenous communities and amongst those who provide health and related services to these communities. Based on the findings of this research project, we suggest the following strategies:

- Continue the development, promotion and distribution of information and community education resources appropriate for indigenous communities, including posters, flip-books, leaflets and videos. Involve indigenous communities in the development of these resources.
- Implement training for existing Aboriginal health workers and Aboriginal health education officers in continence assessment, management and referral. Ensure that core modules on this subject are included in all Aboriginal health worker basic training programs.
- Where possible, create local partnerships between health workers in indigenous communities and specialist continence practitioners for the purpose of providing remote telephone advice and visiting specialist support.
- Incorporate continence information in more general indigenous women’s and men’s health promotion programs, such as ‘Well Women’s’ programs in order to place continence in the broader context of good health and well-being, and to reduce the stigma that might be associated with information sessions focused on incontinence.
- Fund research and demonstration programs for continence education, awareness, assessment and treatment in indigenous communities with a key requirement being active involvement of community members in program development and management.
- Review the assistance and subsidies for continence aids and products available to consumers and carers in remote indigenous communities.


9.6 Ethnic Communities

This research project also considered under-reporting, access and service provision issues for ethnic communities (refer sections 4.9, 5.4, 6.4 and 7.4 of this report). Our consultations with consumer and service provider representatives resulted in the following suggestions:

- Foster linkages between continence nurse advisors and key ethnic community health workers and ethnic community members to provide opportunities for increasing awareness of, and access to, continence services in specific ethnic groups. Linkages and issues may vary across different ethnic groups and communities. Migrant health services and migrant resource centres may provide a good medium for facilitation of these linkages.

- Promote the National Continence Helpline, the Directory of Continence Services and the Guide to Products, to migrant health services and health and community workers in ethnic communities, using an outreach model to assist these services and workers to provide continence information and referral advice to the specific cultural groups with whom they work.

- Continue the development of language translations of continence information pamphlets and the development of generic posters to which individual translations can be applied. Provide translated pamphlets and fact sheets on the national continence website, available for download by health and community workers for their multicultural clients.

- Include information on the appropriate use of interpreters and how to access interpreter assistance in continence information, training and guidelines provided to medical practitioners and other health workers.

- Promote continence awareness amongst interpreter services and encourage the use of appropriate interpreter services in general medical practice and specialist consultation situations involving the discussion of continence issues.

- Complement technical quality control and review processes for any language translations of continence information with consumer-based review, to ensure that consumer-friendly terminology and appropriate level of language has been used.

- Incorporate cultural awareness issues (from the aspects of indigenous and ethnic cultures) in continence training programs for general practitioners, nurses and other health workers.

9.7 Education and Training of Health Professionals

Our review of the research literature (refer Section 3) and consultations with consumers have reinforced the importance of the anticipated and actual response of health practitioners to patient/client reporting of continence problems. The knowledge and confidence of health practitioners and their approach to raising the issue of continence problems with patients/clients play a critical role in encouraging disclosure and achieving a successful continence management and/or treatment outcome.
We received many suggestions from health practitioners, regarding their education and training needs in respect of the assessment, treatment and management of continence problems. We have considered these suggestions along with the findings of the review of the research literature and we propose the following strategies to improve the education and training of health professionals:

1. Develop and distribute national best practice continence assessment guidelines and proformas at three levels of complexity, suitable for use by:
   a) community and residential services (including residential aged care facilities and respite care services);
   b) general practice, community nursing and hospitals; and
   c) specialist continence practitioners.

   These guidelines should include practical advice on how to encourage and manage discussion of continence problems with patients/clients, for example:
   • how to set the scene for discussing continence problems and other sensitive issues (eg providing environmental cues such as posters and pamphlets in the waiting room, ensuring privacy, developing a trusting relationship, providing sufficient time, being aware of cultural issues);
   • key questions to ask and how to ask them;
   • following up on cues from the patient/client;
   • the importance of a positive response; and
   • the advantages of home-based assessment (for example, enabling the health worker to assess environmental factors that may affect the person’s ability to manage their continence and to observe indicators of incontinence that may not be evident in a clinical setting).

   The guidelines for general practitioners should be included or cross-referenced in the Enhanced Primary Care standards and guidelines.

2. Incorporate the national best practice continence assessment guidelines in training curricula for residential care staff, community care workers, nurses and general practitioners.

3. Assist training providers and professional organisations to develop national continence training programs and curricula where these do not already exist, with particular priority on continuing education training programs for general practitioners.

4. Encourage inclusion of continence training modules (preferably nationally consistent in their content) in all basic and undergraduate training programs for health and community workers.
5. Promote the use of competency-based, action learning continence training opportunities for health practitioners, including clinical placements in continence clinics or working alongside continence nurse advisors and specialist medical practitioners in the field.

6. Promote the use of teleconference, videoconference, telemedicine and internet technologies for the delivery of continence (and other) education for health practitioners in rural and remote areas.

7. Prepare a series of clinical updates and articles regarding incontinence and National Continence Management Strategy initiatives for publication in medical, nursing and physiotherapy journals.

8. Provide information, education and guidelines to medical practitioners and other health professionals on the appropriate use of social, behavioural, environmental, physical, pharmacological and surgical interventions for continence problems with an emphasis on the consideration of conservative options in the first instance.

9. Prepare diagnosis-specific continence information in respect of special needs consumer groups (for example, continence issues for people with paraplegia/quadriplegia, continence issues for people with dementia, etc) and make this information available on the national continence website.

10. Prepare, implement and monitor personal care standards, including standards required for the management of incontinence for all residential care services receiving Commonwealth and/or state/territory government funding. Training for residential care staff should also be implemented to support these standards.

As general practitioners are likely to be the first point of health system contact for the majority of people with continence problems, we suggest that this professional group be accorded a high priority in any continence education and training initiatives.

### 9.8 Other Strategies to Improve identification Assessment and Referral of Continence Problems

In addition to improved continence education and training of health practitioners, our consultations have identified the potential for more effective and appropriate assessment and referral practices for continence problems. It appears that there needs to be better networking at a regional level between general health services and continence services/practitioners. Positive results have been reported where such networking already exists.

We therefore suggest promoting the development of collaborative regional networks between local Divisions of General Practice, community nurses and pharmacists, and specialist continence practitioners and continence clinics with the aims of:
• improving knowledge about local continence services (including continence clinics, 
  continence nurse advisors, medical specialists and physiotherapists specializing in 
  this area);
• improving referral practices and providing referral links, where appropriate, between 
  general practitioners and continence nurse advisors; and
• directing continence assessment, treatment and management work to the most 
  appropriate practitioners.

Thought should also be given within these networks to providing gender choice for 
consumers who are particularly sensitive about the gender of the health practitioner.

Another important strategy for improving the identification and assessment of continence 
problems involves general practitioners and nurses including continence screening (and 
assessment where indicated) during routine health procedures for women (eg when 
performing breast checks and Pap smears) and for men (eg in conjunction with prostate 
checks). Such routine clinical practice may overcome several of the major reasons for 
not reporting continence problems.

9.9 Recommendations

This research project has identified a broad range of strategies that are required to address 
the issues of under-reporting of incontinence and the barriers to accessing appropriate 
continence services. These strategies fall within the purview of a range of government 
portfolios (at Commonwealth and state/territory levels), regional health 
services/authorities, universities and other training and professional institutions. 
Following discussion with representatives of the Commonwealth Department of Health 
and Aged Care which commissioned this research, recommendations that can be 
addressed within the Department’s scope of responsibilities have been formulated. These 
recommendations appear below.

The recommendations do not attribute specific responsibility for action. The service 
system is complex and, in some instances, there will need to be shared action (between 
Commonwealth and state/territory governments, between government and non-
government organisations and between various service providers) in order to achieve the 
objectives suggested in the recommendations. It is suggested that the Commonwealth 
Department of Health and Aged Care take a coordinating or facilitating role through the 
National Continence Management Strategy to action the recommendations of this report.
Recommendation 1
Conduct a staged national community awareness strategy to improve community understanding of incontinence and the options for managing, treating and preventing continence problems, consistent with the aims and strategies outlined in Section 9.1 of this report.

Recommendation 2
Provide improved access to appropriate continence information for consumers and carers with reference to the strategies suggested in Section 9.2 of this report.

Recommendation 3
Develop and promote continence information, resources, training and services for indigenous communities with consideration of the strategies suggested in Section 9.5 of this report.

Recommendation 4
Extend the reach of continence services, programmes and community awareness strategies into ethnic communities with reference to the suggestions contained in Section 9.6 of this report.

Recommendation 5
Facilitate the education and training of health professionals, particularly general practitioners, in respect of assessment, treatment and management of continence problems, using the strategies suggested in Section 9.7 of this report where appropriate.

Recommendation 6
Facilitate improvement in the identification, assessment and where appropriate, referral of continence problems by encouraging local collaboration between general health practitioners and continence practitioners and by encouraging health practitioners to incorporate continence assessments in routine health screenings for women and men.

9.10 Priorities for Action
The six recommendations and suggested strategies documented above are the result of broad-based consultation with a wide range of stakeholder groups who raised extensive issues in respect of continence problems. It is recognized that the depth and breadth of the recommendations may require a lengthy period of implementation and so we suggest the following areas as priorities for action:

- Changing community attitudes towards, and knowledge of, incontinence.
- Improving access of consumers and carers to appropriate, accurate and relevant information about incontinence.
- Developing the knowledge, skills and clinical practice of general practitioners, with particular attention to the skills required to increase reporting of continence problems.
9.11 Issues Beyond the Scope of the National Continence Management Strategy

A number of important issues and suggestions raised by stakeholders during consultations were considered to be beyond the scope of the National Continence Management Strategy.

Costs of Continence Management

Consumers were particularly concerned about the costs of continence management and the limitations in eligibility, access and assistance in aids and equipment subsidy schemes. The cost of continence pads and other continence aids were reported as a major burden, particularly for pensioners and those ineligible for aids and appliance assistance schemes.

The costs associated with obtaining assessment and treatment of continence problems were also an issue for consumers. These costs included charges for physiotherapy and in some cases pathology and radiology services and the cost of transport to and from assessment and treatment sessions. Such costs were particularly felt by people living in rural and remote areas and locations where specialized continence services were not readily available through the public health system.

Access to Services

As noted in sections 9.3 and 9.4 of this report, the level of access to appropriate continence services for consumers and carers needs to be improved. The access difficulties reported by consumers, carers and service providers consulted for this research involved not only a sparcity of health practitioners and clinics providing specialized continence services (particularly in rural and remote areas) but also a lack of training and awareness regarding continence assessment and treatment options amongst general health practitioners.

These issues suggest the need for an increased profile for continence assessment, management and treatment amongst generic health services, as well as strategies to increase the number and geographic spread of continence specialists and clinics. A concerning theme arising from the stakeholder input to this research was a reported tendency for health practitioners to accept incontinence amongst older people as an inevitable consequence of ageing with a low level of referral and intervention for this population.

The research team strongly suggests, that these access issues be considered by the relevant state, territory and regional health authorities. Tertiary education providers and professional bodies may also be able to assist by promoting continence training opportunities for health practitioners in rural and remote areas.
Other Issues

Other issues raised by consumers included:

- the availability and eligibility criteria for home modifications assistance related to continence and hygiene care;
- the need for a national rating system for continence pad absorbency; and
- practical and feasible design features and facilities that could be incorporated in existing and new public toilets to assist consumers and carers to manage continence problems.

While it is acknowledged that this research project does not have the ambit to guide the activities of other departments or organisations, the research team hopes that the findings of this research will be considered by the relevant organisations in future planning and development of services and programs.
Bibliography


Royal Australian College of General Practitioners, 2000, *Enhanced Primary Care: Standards and guidelines for the Enhanced Primary Care Medicare Benefits Schedule items*, Commonwealth Department of Health and Aged Care, Canberra.


