

Aboriginal and Torres Strait Islander continence training in rural and remote Australia

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Ailsa Sutherland is a registered nurse who has a graduate diploma in primary health care. She is a continence nurse working with the Continence Foundation of Australia doing special projects and she also works in a continence clinic with Western Health in Victoria.

Ailsa spent three years in the Kimberley region in Western Australia working with Indigenous populations—95% of her clients were Indigenous people from remote communities. During that time she became aware of the gap in services between remote and city regions. She also became aware of the language barrier that can result in poor communication between health professionals and local people. Ailsa was responsible for initiating the Kimberley language tool, which translated health messages into different Kimberley languages. A linguist and teacher/photographer assisted in this project.

In 2008 Ailsa was part of the Federal Government's Aboriginal and Torres Strait Islander continence working party to look at ways to increase awareness of continence issue amongst Indigenous people.

In the last two years Ailsa has been adapting the Certificate II in Continence Promotion and Care for Indigenous health workers and delivering that course in remote areas around Australia. She has also been involved in consulting with Indigenous groups to update and improve the range of Indigenous continence brochures.

Introduction

Background

Incontinence is a common health condition with significant physical, social and economic implications. Current research indicates that 4.6 million people in Australia or 21% of people living in the community are affected by some degree of incontinence. ⁽¹⁾ Despite its high incidence, incontinence is too often accepted as 'just a normal part of ageing'. In reality, incontinence affects every age group and is common co-morbidity with a range of life stages (e.g. pregnancy or menopause) and chronic conditions (e.g. diabetes or asthma). In addition to this, there are a range of factors which put people at a higher risk of incontinence, including:

- being overweight or obese
- being female
- having a baby
- smoking, or
- excessive alcohol consumption.

Very few studies have investigated the prevalence of incontinence amongst Indigenous Australians, although Millard et al ⁽²⁾ reported that the prevalence of urinary incontinence among Aboriginal women living in rural areas is likely to be high. Considering the increased prevalence of some chronic conditions amongst Indigenous communities, incontinence is believed to be a problem among a higher than average number of Indigenous people.

As the peak body for continence promotion, management and advocacy, the Continence Foundation of Australia (CFA) works to 'raise community awareness about bladder and bowel health and the prevention of incontinence.' ⁽³⁾ These awareness-raising and education activities target all segments of the community, and recently the CFA has undertaken a number of projects targeting health professionals who provide services for Indigenous Australians in rural and remote regions.

Cultural barriers

These projects included strategies to overcome the cultural barriers surrounding incontinence, as bladder and bowel control problems 'cause much shame for Aboriginal or Torres Strait Islander people... [and are] not well understood amongst these communities or openly discussed'.⁽⁴⁾

A study undertaken by Pearson⁽⁵⁾ for the Australian Government Department of Health and Ageing looked at the reasons people don't seek help for incontinence. It was found that for Aboriginal people, although many of the reasons for not discussing continence problems were similar to those reported by other cultural groups (i.e. embarrassment), 'the issues [are] compounded by traditional cultural mores, and socio-economic and environmental factors'⁽⁵⁾, including 'shame issues and shyness for Aboriginal people when talking about body functions'⁽⁵⁾ and being 'reticent to seek help'.⁽⁵⁾

Fear also plays a role in the reluctance to discuss incontinence as a strong connection to the land means elderly Aboriginal people fear being placed 'out of their country ... in a nursing home in town if they admit to a continence problem'.⁽⁵⁾ Compounding these cultural factors are other issues such as a lack of suitable information resources about incontinence, low literacy and a greater likelihood of living in a rural or remote community without access to continence services.⁽⁵⁾

Logistical barriers

There are numerous barriers for Indigenous Australians when it comes to accessing health services. In addition to the stigma or 'shame' of incontinence, other factors such as the often large geographic distance between health services, a lack of transport in some remote areas, financial difficulties, limited culturally appropriate services, and sometimes limited English skills⁽⁶⁾ negatively impact access to continence-specific health care by Indigenous Australians. The availability of Indigenous staff is a key factor in whether Indigenous Australians can effectively access health services.^(7; 8; 9) In 2005, approximately 11% of Indigenous Australians reported difficulty understanding or being understood by health service providers, for those living in remote areas the number rises to 19%.⁽⁶⁾

Research has demonstrated the benefits of services being 'provided by appropriate people, in the right location, using culturally appropriate materials and an approach that encourages active participation'.⁽⁵⁾ Indigenous health workers establish trust and form connections with their community, therefore increasing the number of Indigenous health workers and health services with skills and knowledge in continence promotion and care is one way of overcoming the cultural and logistical barriers.

Project description

Part one—accredited training

Scoping research

The CFA undertook scoping research to measure current availability of resources and support for Indigenous people in rural and remote communities, as well as gauge awareness levels of the issue of incontinence. This research was undertaken with approximately 100 Indigenous health services, and revealed:

- almost a quarter (22%) believed there was no incontinence within their community
- over half (52%) did not provide services for incontinence
- 87% were not aware of state and federal funding schemes that subsidise an individual's incontinence product costs
- 88% did not know about the Aboriginal and Torres Strait Islander continence brochures and resource materials available through the Australian Government, and
- 88% had not heard of the National Continence Helpline, a free service managed by the Continence Foundation providing advice to individuals, carers and health professionals.

These low levels of awareness may be a result of a lack of continence education for Indigenous health workers—only one respondent could recall undertaking any continence-related learning in the courses they undertook. Other respondents felt they did not have the confidence and knowledge to discuss bladder or bowel control problems without support, or that time restraints meant there were more urgent priorities. These results reinforced the need to increase the support, education and training available to Indigenous health workers in continence promotion and care.

Accredited training review and rollout

To address the lack of knowledge and confidence surrounding incontinence, the Continence Education in Rural Australia Program (CERAP) was established in 2009. With the goal of empowering Indigenous health workers to screen, assess and deliver appropriate treatments for their people who are affected by incontinence, the program specifically aimed to:

- up-skill health workers in remote locations on the management of incontinence by providing accredited education
- increase health worker confidence to discuss incontinence issues with their community members
- increase responsiveness from health workers to presentations of symptoms relating to incontinence
- provide Indigenous people a more equitable level of access to State and Federal Government continence product subsidy schemes, and
- increase continence knowledge in remote areas where specialist continence health professionals are not available.

The CFA, in partnership with Benchmarque Registered Training Organisation, had previously developed three courses in continence promotion and care—a short course, Certificate II and Graduate Certificate. These courses formed the basis for the CERAP accredited training and a multidisciplinary team was formed to review and modify the courses. The modifications included:

- making the courses more culturally appropriate and specific
- removing the pre-reading requirement to ensure all competencies are taught entirely during the face to face sessions
- altering course assessments so they are completed using group work and verbal answers to keep writing to a minimum
- face to face delivery of the entire course, and
- developing presentation and demonstration aids appropriate to remote and Indigenous contexts.

The additional presentation and demonstration aids were designed to suit people who may have a first language other than English and included DVDs, jigsaw puzzles, case studies and felt anatomy pieces. The DVDs, developed in partnership with the General Practice Network Victoria, formed a major presentation tool and were developed using MARVIN animation software. MARVIN is a character-based animation tool, which has the ability to add pre-recorded voices in any language, backgrounds, music and more. This means the content is uniquely tailored to the audience. Content covered in the course includes:

- basic anatomy of the bladder and bowel
- types of incontinence and their risk factors
- management of the types of incontinence
- types of continence products
- who to go to for more help

- how to get funding for eligible clients, and
- for men only, a session on the prostate.

Training was planned for delivery from the end of March 2009 through to the first week of June 2009, and a consultative process guided the selection of training locations. Training took place in 18 towns and communities in rural and remote areas of Queensland, New South Wales, South Australia, Northern Territory and the Kimberley and Pilbara regions in Western Australia.

When visiting the towns, face to face training and assessment was delivered as well as other awareness raising activities with the broader community. These additional awareness raising activities targeted multidisciplinary team members and health managers who may not have undertaken the accredited continence course. Overall, the focus was to build local capacity rather than deliver a continence service, as well as form, maintain and strengthen local networks to support existing practice.

Accredited training evaluation

In total throughout 2009, training was delivered to 273 health workers in 18 locations (see diagram 1). Almost half of the participants had no previous training in continence education despite many having a vocational qualification as Aboriginal and Torres Strait Islander health workers or in aged care. Of those who had undergone continence training previously, many had done a short course run by companies selling continence pads.

The majority (64%) of health workers undertook the Certificate II course, with 36% completing the short course. A comparison of evaluation results between the short course and the Certificate II revealed that the full day training for Certificate II was the preferred length. Some students who attended the short course suggested they would have liked a longer session, however time and staffing constraints meant some organisations were unable to release students for the full day.



Diagram 1 Training locations

Given incontinence is such a 'shame' topic, the evaluation assessed whether students had gained the confidence to use the information in the future. Pleasingly, results showed 93% of participants had increased confidence talking to people about continence, and 98% would use the information in the future (see Table 1).

Table 1 Previous continence education

Previous continence education	%
No prior training	54%
Short course	26%
University	5%
TAFE or vocational training	4%
Conference	2%
Did not answer	9%
	100%

The training course aimed to provide practical knowledge that participants could use in the future. 98% stated that their continence knowledge had increased, and 70% of students felt that they would use the information in the future. The majority of these thought they would incorporate part or all of the learning into aspects of their work role depending on their area of work (see Table 2).

Table 2 Use of continence knowledge in the future

Use of continence education in the future	%
As part of my role	34%
Encouraging discussion and advising about continence with clients	11%
Education	9%
With family and friends	6%
Improved continence assessments for chronic disease and women's health	6%
Refer clients to seek assistance	2%
Pelvic floor exercises and support networks	2%
Did not answer	30%
	100%

The face to face training was regarded as more beneficial than other delivery methods as students stated that they liked to work in groups and gain information from other student's experiences. Table 3 below shows which elements of the course participants most enjoyed. Over half the participants stated they enjoyed 'all of the session'. Of those who selected a specific element of the course as their favourite, 12% enjoyed 'anatomy' the most followed by 10% who selected 'activities, DVD and case studies'.



Table 3 Most enjoyable part of training

Part of training most enjoyed	%
All of the session	53%
Anatomy	12%
Activities, DVD and case studies	10%
Presentation and style of delivery	7%
Continence products	6%
Pelvic floor exercises	5%
Other	2%
Did not answer	5%
	100%

When asked what should be changed about the course, the majority believed there should be no change to the training. Many stressed that it was excellent and demonstrated cultural awareness and sensitivity.

These results indicate that the training achieved the aim of developing knowledge, skills and confidence for continence promotion and care. Training continued throughout 2010 with a further 40 students receiving scholarships to undertake training, and 280 scholarship places planned for 2011-2014.

Part two—Indigenous resource review

Project driver

During the delivery of accredited training across Australia, many students provided feedback indicating that the existing range of Australian Government Indigenous continence brochures needed to be reviewed. The brochures, originally developed in 2001, were due to be reviewed and this provided an opportunity to engage Indigenous communities from across Australia in a consultation process.

Work commenced on reviewing the range of brochures in early 2010, with the major finding being that the existing range of brochures was adequate in meeting the needs of urban dwelling Indigenous Australians. However, there was a need to adapt the brochures to meet the needs of remote communities, for whom English can be a second or third language. Specifically, feedback indicated that there was not enough visual information included in the existing brochures and they needed to be more culturally specific.

This feedback was particularly important, as research shows that to encourage a change in target audience behaviour we need to do more than just educate people about their health⁽¹⁰⁾—we need to understand the drivers of the current behaviour and the barriers to change. Insight to current behaviour, awareness levels and barriers to change had been gathered during scoping research for the CERAP, providing valuable insight when drafting text and images for the new brochures.

A set of draft brochures was developed and taken for consultation with groups in Victoria, New South Wales, Queensland, the Northern Territory, South Australia and Western Australia. The final images and text were decided on as a result of the consultation process, and included an emphasis on everyday language such as 'wee', 'grog' or 'yarn about it'. It became clear during consultation that we needed to use direct, everyday language to avoid confusion or misunderstanding.

Illustrations used throughout the brochures enhance the relevance of the information. For example, a brochure titled 'Leaking pee after having a baby' uses a set of images to demonstrate which part of the body is shown in the close-up anatomical picture of the womb, bladder, vagina and bowel (see Diagram 2 below).



Diagram 2 Images used in the ‘Leaking pee after having a baby’ brochure

New range of brochures

Consultation also revealed a variety of ways in which the brochures could be used, either by health professionals or their patients. This was taken into consideration during development of the final versions, resulting in brochures that are designed for use in any of three ways:

- the brochures have been designed so that Indigenous health workers in remote areas can themselves, increase their knowledge of incontinence
- the brochures can be displayed in the health service for anyone to pick up and read—specific men’s business and women’s business brochures are clearly marked, making it easier for centres that have separate gender-specific service areas, and
- the layout of the brochures allows Indigenous health workers and other health professionals to use the brochures to talk about a range of topics with their clients, which explains the tag line of “Let’s yarn about this” featured across the new range. The range of topics is shown in Table 4 below.

Table 4 New range of Indigenous brochures

Topic	Title
Alcohol	Grog, pee and poo trouble—Let's yarn about this
Bedwetting	Kids wetting the bed—Let's yarn about this
Bladder training	Training the bladder—Let's yarn about this
Continence products	Pads, clothes and bedding to help if you are wet—Let's yarn about this
Constipation	Hard poo (constipation)—Let's yarn about this
Diabetes	Diabetes and pee or poo problems—Let's yarn about this
Functional incontinence	Help getting to the toilet—Let's yarn about this
Pelvic floor muscles exercises for men	Men and strong pelvic floor muscles—Let's yarn about men's business
Pelvic floor muscles exercises for women	Strong pelvic floor muscles for women—Let's yarn about women's business
Pregnancy	Leaking pee after having a baby—Let's yarn about women's business
Prostate	Pee problems and the prostate—Let's yarn about men's business
Urinary incontinence	Leaking pee—Let's yarn about this

The brochures were launched at the National Conference on Incontinence in Alice Springs on the 28th of October 2010. Results so far indicate a strong uptake of the brochures with over 21,000 brochures ordered and distributed in the three months following the launch.

Discussion

Findings from this project highlight the importance of geographically accessible training in rural and remote locations, and of using a variety of teaching methods. When developing information resources it is imperative that wide consultation with a range of Aboriginal and Torres Strait Islander groups is undertaken and should take into account differing literacy levels and cultural needs.

Some important lessons have been learnt along the way, with the most important one being that the CFA must continue to raise awareness among Indigenous health services and health workers that incontinence is a major health issue which seriously affects quality of life across the age span.

The formation of partnerships with key organisations that can incorporate educational continence information into their existing programs will also assist with raising awareness. Health workers in the fields of men's health, women's health, chronic disease management, health promotion, aged care and disability services are often working with clients that have a high risk of incontinence. By including continence education into existing vocational training this will increase their knowledge, minimise the use of pads, reduce the cost of aged care and most importantly, improve the dignity and quality of life for clients.

When planning the education sessions, there was difficulty contacting managers, educators and students over the months of December and January due to the wet season. In many areas in remote Australia people often move from remote areas into towns as their community may be subject to flooding and roads can be cut off. Holidays are taken at this time of year. In some communities this may be a time of initiation, 'lore' for men. Ideally, training is usually scheduled after the wet season and often starts in April. The CERAP training commenced in March and was too early for many people. Unfortunately, delaying the training was not possible due to project timelines. Additionally, funerals and sorry business in some locations impacted on our ability to know participant numbers in advance of each session and resulted in lower numbers of students. When planning training in remote areas these factors will always need to be considered and are often beyond the control of the trainer. Cultural events need to be understood and have priority.

Sourcing trainers for the program proved to be more difficult than expected. Trainers are selected based on their experience in providing continence services to Indigenous communities. However, many continence nurses in remote regions, while positive and supportive about CERAP, were not available or confident to participate as trainers due to work and travel constraints. The original project plan envisaged that a number of trainers would be involved, however all sessions in 2009 were delivered by one trainer. It was not until 2010

that the team of trainers was able to be expanded from one to three. These trainers all bring with them a strong network of contacts which is invaluable to the success of the project.

Sustainability of the program was enhanced by supporting nineteen health professionals (mostly registered nurses) to complete the Graduate Certificate in Continence Management. These professionals agreed to provide support and education in their areas of work with their staff and colleagues. This helps support the low number of continence nurses in remote Australia. For example, in the Northern Territory there are 1.5 continence positions. Two additional nurses who completed the training now provide continence advice to clients. While they will not work only in continence, they will incorporate continence into their current work practices.

Conclusion

The Continence Education in Rural Australia Program (CERAP) has empowered participants to effect change in their workplaces, communities and families and has increased their confidence to talk about continence issues. To support this knowledge, health workers and other health professionals are now using culturally appropriate resources that have been specifically developed to suit their needs. The time and money invested in extensive consultation with groups from across the country have been key to ensuring the training and brochures are culturally appropriate and practical.

Note: Although this paper refers to Indigenous Australians and communities, the consultation and training sessions were attended by a majority of Aboriginal people and included only limited representation of Torres Strait Islander people. This will be addressed in 2011 with sessions planned for some groups in the Torres Straits.

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