Submission to the

Royal Commission into Aged Care Quality and Safety

Continence Foundation of Australia

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Rowan Cockerell, CEO, Continence Foundation of Australia

r.cockerell@continence.org.au

Executive Summary

Incontinence is a highly personal and stigmatised condition which can often be treated, improved or better managed. It can also have profound negative effects on those living with incontinence and their carers, restricting their interactions with family, work and the community. Because of the stigma and shame, many people and their carers keep their condition secret, which adds an extra dimension of suffering and leads to social isolation, higher psychological impact and delayed help-seeking. Despite its health, social and economic consequences, incontinence is often considered a normal part of ageing and thus is not well understood or prioritised in care for older Australians, particularly those living in residential aged care facilities.

Incontinence is one of the top three critical factors identified for older Australians needing to transition from home-based aged care to residential aged care facilities. Faecal incontinence increases the risk of being recommended for residential care by 86%, and urinary incontinence by 39% (compared to 83% for a diagnosis of dementia).

An estimated 1.17 million community-dwelling Australians aged 65 years and over were living with incontinence in 2010. In the same year, an estimated 128,473 residents (71%) in aged care facilities had urinary or faecal incontinence or both. The number of residents with these conditions is projected to increase to 253,113 by 2030.

Currently, continence care and incontinence management are not being managed effectively. Since 2015, complaints regarding continence management in residential aged care to the Aged Care Quality and Safety Commission (and the Aged Care Complaints Commission before that) have ranked in the top 5 most common issues subject to complaint.

Even if people have been experiencing long-term incontinence, it is never too late to be assessed, and strategies implemented, to treat, improve or better manage bladder and bowel problems. When the dignity and personal preferences of those in aged care are prioritised and continence assessments are undertaken and treatment and/or management strategies are implemented, significant improvements in continence can be achieved in the elderly and those with disability.

The Continence Foundation of Australia

The Continence Foundation of Australia (the Foundation) represents Australians with or at risk of incontinence, their carers and associated health professionals. The Foundation's long history and diverse and expert membership gives it an unrivalled understanding of issues relating to safe and effective incontinence care and management. Its membership represents the continence sector and workforce who were consulted in the development of this submission.

In this submission to the Royal Commission into Aged Care Quality and Safety, the Foundation presents evidence, according to the Terms of Reference, concerning:

- aspects of the quality and safety of aged care services, specifically dignity, choice and control, clinical care and personal care, and
- the critical role of the aged care workforce in delivering high-quality, safe, person-centred care, and the need for close partnerships with families, carers and others providing care and support in all forms of Commonwealth-funded aged care services, whatever the setting or environment in which those services are delivered.

The purpose of this submission

The Foundation wishes to raise the issue of continence care and incontinence management in the aged care setting, in both residential aged care facilities and in the community, by highlighting:

- safe and effective continence care as a human rights issue, supporting dignity and quality of life through person-centred care,
- the issues and challenges related to current continence care, and
- the potential for harm from unsafe and ineffective continence care and incontinence management, including urinary tract infections, incontinence-associated dermatitis, pressure injuries and falls (which may result in avoidable emergency department admissions), functional decline, depression, reduced quality of life and, for those living at home, increased risk of admission into residential aged care.

Safe and effective continence care is central to consumer dignity and choice. Continence care should be informed by personal choice and the maintenance of dignity in accordance with the wishes and preferences of the individual or those making decisions on their behalf.

It is the responsibility of those caring for the continence needs of disabled or older Australians accessing aged care services to strive to maximise their dignity, quality of life and mental and physical health.

Recommendations

To ensure disabled and older Australians accessing aged care services receive person-centred, dignified continence care, the Foundation recommends that:

1. Consumer dignity and choice should be central to the screening, assessment and management of incontinence in aged care services consistent with the Aged Care Quality Standards.
    - Aged care providers must ensure that individualised continence care plans are developed which will identify and consider personal preferences (informed choice), maximise dignity, include toileting assistance, maximise ability and include re-enablement.
    - Dignity must be maintained according to the consumer or their nominated person's preferences.
    - Suitable evidence-based resources for screening, assessment and reassessment of continence care and incontinence management and treatment must be used for disabled and older Australians accessing all levels of care within aged care services.
2. Incontinence should be acknowledged as a cost driver in RACFs and must be funded adequately.
    - Funding in any implemented funding/care structure (including the proposed Australian National Aged Care Classification funding model) must acknowledge incontinence as a significant cost driver in RACFs.
    - Ensure adequate funding for safe and effective continence promotion, care and incontinence management for all residents in RACFs.

3. Continence education must be a mandatory requirement for all health professionals and personal care workers who provide care and treatment to disabled and older Australians accessing aged care services.

    - All staff and health professionals who provide care and treatment in aged care services, including personal care workers, enrolled nurses, registered nurses, nurse practitioners, therapists, general practitioners and geriatricians, must (1) receive education about safe and effective continence care and management in their foundation courses (VET and undergraduate courses) and (2) have regular, ongoing professional development and training in continence management.
    - Review of the content of the qualification for personal care workers [Certificate III in Care Support (Ageing)], who provide most continence care, must recognise the need to build capacity in continence care (which, at present, it does not).

Contents

Introduction

Incontinence is an intensely personal and stigmatised condition which can often be treated, improved and better managed. Despite its health, social and economic consequences, it is considered by many as a normal part of ageing and thus is not well understood or prioritised in care for older Australians, particularly those living in residential aged care facilities (RACFs).

Incontinence can have profound negative effects on the lives of both those with incontinence and their carers (formal, family, paid and unpaid). Because of the stigma and shame, many people and their carers keep their condition a secret, which adds an extra dimension of suffering and leads to social isolation, higher psychological impact and delayed help-seeking.

Providing people with incontinence with aids, such as pads and catheters, is not the sum of what constitutes safe and effective continence care. Much more is required for the promotion of continence and the care, management, treatment and resolution of incontinence. Safe and effective continence care needs to be active, not passive, and active continence care is likely to cost more.

Safe and effective continence care is central to consumer dignity and choice. Continence care should be underpinned by informed personal choice and the maintenance of dignity in accordance with the wishes and preferences of the individual or those making decisions on their behalf.

It is the responsibility of those caring for the continence needs of disabled or older Australians accessing aged care services to ensure that care maximises their dignity, quality of life and mental and physical health.

Incontinence in aged care settings: a snapshot

Incontinence describes any accidental or involuntary loss of urine from the bladder (urinary incontinence) or faeces or wind from the bowel (faecal incontinence). Incontinence is a widespread condition that ranges in severity from 'just a small leak' to complete loss of bladder or bowel control.[1]

Incontinence is common, particularly as people age, but only half of older people with incontinence seek help for their symptoms.[2] The most common reasons for not seeking help are the presence of mild symptoms, a belief that incontinence is a normal part of ageing and a belief that nothing can be done about incontinence.[2-4] Additionally, those with incontinence often dismissed the condition as unimportant.[4]

Incontinence and inadequate continence care can lead to a loss of dignity. An Australian study of frail, older RACF residents found that urinary incontinence was strongly associated with a loss of dignity and independence, which had a detrimental effect on institutionalised older residents' health-related quality of life.[5]

There are many risk factors for incontinence in disabled and older Australians, these include, but are not limited to:

- comorbid medical conditions: diabetes, chronic pulmonary disease, congestive heart failure, degenerative joint disease and sleep apnoea;
- neurological and psychiatric conditions: stroke, Parkinson's, dementia and depression;
- severe constipation and faecal impaction;

- functional impairments: impaired mobility, including impaired hand dexterity and impaired cognitive function;
- medications; and
- environmental factors: inaccessible toilets, unsafe toilet facilities and unavailable caregivers for toileting assistance.[6]

Incontinence is prevalent within the older community-dwelling Australian population. In 2010, an estimated 1.17 million community-dwelling Australians aged 65 years and over were living with incontinence, and 128,473 Australians living in RACFs – a number projected to increase to 253,113 by 2030.[7] In Australia in 2010, 71% of residents in aged care facilities were living with urinary or faecal incontinence or both.[7] More recent data confirms that incontinence continues to be highly prevalent within the aged care sector, with 75–81% of people in RACFs living with the condition.[8] This is consistent with international data that suggests the prevalence of incontinence in residential aged care facilities is high and, depending upon report, varies between 60–90% of all residents.[9]

Incontinence is one of the top three critical factors identified for older Australians needing to transition from home-based aged care to residential aged care.[10] It can also increase the risk for recommendation to residential care by Aged Care Assessment Teams (ACATs). The *Aged Care Assessment Program National Data Repository Annual Report 2007-2008*[11] set out data relating to the assessment of clients for aged care services by ACATs. Risk factors for a recommendation for residential aged care were identified. Urinary incontinence and faecal incontinence were found to be in the top four condition-related risk factors influencing recommendations to residential care, along with confusion and dementia.[11]

According to Aged Care Funding Instrument (ACFI) data, in 2009, 67% and 55% of residents of aged care facilities were found to need care for urinary incontinence and faecal incontinence, respectively.[1] Half of residents (54%) experienced more than three episodes daily of urinary incontinence or passing of urine during scheduled toileting, and 35% experienced more than four episodes per week of faecal incontinence or passing faeces during scheduled toileting.[7]

Half (51%) of all residents in RACFs with an ACFI assessment also have a formal diagnosis of dementia.[12] Residents with dementia have high needs for physical assistance with toileting and continence care. Australian research found that 76% of residents diagnosed with dementia had the highest rating of need for assistance with continence, and 68% with toileting. In comparison, of RACF residents without dementia, 51% had the highest care need rating with continence and 47% with toileting.[13] Sixty-nine per cent of residents with dementia were recorded as having more than three episodes of urinary incontinence daily or scheduled toileting, while 46% of residents living with dementia had more than four episodes of faecal incontinence weekly or scheduled toileting.[14] It is more difficult to provide continence care for people with dementia because the condition may affect their awareness of their bladder and bowel needs.

The way incontinence is perceived by the public, formal and family carers, and health professionals has a profound impact. Surprisingly, incontinence can be both stigmatised and normalised or

[1] This is not the proportion of residents who have a diagnosis of incontinence, because those who could self-manage their incontinence were not included. Thus, these are underestimates of the proportions of residents with incontinence.

considered both normal and undignified at the same time, and these perceptions act as barriers to disabled and older Australians receiving person-centred, dignified care. People living with incontinence are stigmatised[15] as are the people who care for them.[16] The shame and embarrassment of revealing their incontinence prevents people from seeking help and advice.[4]

Staff perceptions about continence care and incontinence management are also important. A recent Australian study found that many staff in aged care facilities believe incontinence is intractable and undignified. Consequently, they undertake continence care that they perceive will preserve dignity, but limit it to cleaning, containing and concealing incontinence rather than adopting active management approaches to prevent, minimise or treat incontinence. By not taking into account personal preferences and hindering individual capacity to develop continence, staff are unintentionally reducing the dignity of residents rather than protecting it.[17]

Active promotion of continence care and incontinence management, including toileting assistance, requires investment. However, it generates considerable benefits, including optimising dignity and long-term cost savings by reducing the number of incontinence products used, urinary tract infections (UTIs), incontinence-associated dermatitis and pressure injuries, and functional decline.

It is never too late to treat and improve

Even if people have been experiencing long-term incontinence, it is never too late to be assessed and strategies implemented to treat, improve or better manage bladder and bowel problems.

The continence care and incontinence management that frail elderly Australians receive is of particular concern. An attitude that they are too old and unlikely to benefit from a continence assessment and treatment may be limiting their care. A national audit of continence care in RACFs in the United Kingdom found that ageism contributed to low standards of care for incontinence in elderly residents:

Older people received particularly poor care, even though they suffer more from incontinence Overall, quality of care appeared worse for older people (patients aged 65 years and over as compared with those aged <65) even though older people suffer more from incontinence. This is unequal provision of health care. There remained much room to involve older patients in their own care of what is often a distressing, yet curable condition.[18(p10)]

An Australian audit has not been conducted, but the high number of complaints about unsafe and ineffective continence care to the Aged Care Quality and Safety Commission, and the Aged Care Complaints Commission before that, confirm that, in many instances, continence care is not being managed well in Australian RACFs (see *Quality and safety in aged care* below).

Significant improvements in continence can be achieved in the elderly and those with disability. Studies of conservative treatment for urinary incontinence in elderly women, have shown improvements can be made. Three randomised controlled trials compared the effectiveness of Pelvic Floor Muscle Exercises (PFME) combined with physical exercise for 3 or 5 months (intervention group) in women living at home with mean ages of 77, 76 and 82 years with women who did not do PFME and did gentle or no other exercise (control group). When the results of the studies were combined in a meta-analysis, a significantly higher cure rate (complete cessation of urine leakage episodes) and a subjectively lower urinary leakage score was found in the intervention group compared with the control group.[19]

The use of medications can also lead to improvements in urge urinary incontinence. A systematic review[20] found high-level evidence that three medications (oxybutynin, trospium, and darifenacin) improved urge urinary incontinence in older people. Oxybutynin reduced the frequency of urinary incontinence in frail community-dwelling older people.

Incontinence is a common consequence of acquired brain injury.[21,22] Many people with an acquired brain injury are dependent on staff intervention, in some cases from more than one staff member, to assist with toileting. Toileting for people who are reliant on others for assistance not only reduces their independence, but also profoundly impacts their quality of life.

An Australian study was undertaken to determine whether a comprehensive continence assessment, individually tailored management plans and assistive products could support people with acquired brain injuries to toilet more independently and improve their quality of life.[23] Following a comprehensive continence assessment, a continence management plan was prepared by a qualified continence expert and recommendations made. The use of assistive products, as part of a more comprehensive continence management plan, was shown to reduce care hours for toileting and continence care and incontinence management and increase the independence of the study participants.

When the dignity and personal preferences of those in aged care are prioritised and continence assessments are undertaken, and treatment and/or management strategies are implemented, significant improvements in continence can be achieved in the elderly and those with disability, improving their quality of life.

Recommendation 1

Consumer dignity and choice should be central to the screening, assessment and management of incontinence in aged care services consistent with the Aged Care Quality Standards.

- Aged care providers must ensure that individualised continence care plans are developed which will identify and consider personal preferences (informed choice), maximise dignity, include toileting assistance, maximise ability and include re-enablement.
- Dignity must be maintained according to the consumer or their nominated person's preferences.
- Suitable evidence-based resources for screening, assessment and reassessment of continence care and incontinence management and treatment must be used for disabled and older Australians accessing all levels of care within aged care services.

Human rights, dignity and person-centred care

Australia has ratified international human rights instruments that contain important provisions relevant to the provision of aged care services. These instruments provide a framework for policy and legislation at the national level related to the protection of the human rights of our most vulnerable citizens — the aged, the frail and the disabled — and the promotion and protection of their health.

The *Universal Declaration of Human Rights*[24] sets out the fundamental human rights that must be universally protected and recognises that these rights derive from the inherent dignity of the human person. Central to human rights is the protection of those most at risk.

The *International Covenant on Economic, Social and Cultural Rights*[25] entered into force in 1976. The rights that the Covenant seeks to promote and protect that relate to this submission include:

- the right of self-determination;
- the right to social protection;
- the right to the highest attainable standards of physical and mental health; and
- the right to enjoy the benefits of scientific progress and its applications.

The *Convention on the Rights of Persons with Disabilities*[26] entered into force in 2008. The rights that the Convention seeks to promote and protect that relate to this submission include:

- the right to social protection without discrimination on the basis of disability;
- the right to respect for their physical and mental integrity on an equal basis with others; and
- the right to enjoy the highest attainable standard of health without discrimination on the basis of disability.

Common to the Covenant and the Convention is the acknowledgement that the right to social protection and the right to the highest attainable standards of health are fundamental human rights. These are not ideals, but high-level expectations that should underpin the functioning of a society that cares for its most vulnerable citizens: the aged, the frail and the disabled. The treaties should be

acted on and used to inform the development of legislation, policies, programs and the provision of services to protect and promote the human rights of those accessing aged care services.

In the Foundation's view, safe and effective continence care, which promotes choice and dignity and results in the highest possible standards of health, is a fundamental human right.

A *Dignity in Continence Care Framework*[27] places the concepts of dignity and care central to the delivery of safe and effective continence care and incontinence management and treatment. This framework is underpinned by elements which include:

- adopting an empathetic approach;
- respecting personhood in dementia;
- communicating therapeutically;
- promoting an authentic partnership;
- acknowledging stigma, social taboos and courtesy stigma; and
- conducting a foundational assessment.

The framework states that the goal of a foundational continence assessment (an assessment for care planning) is to help identify:

- levels of support required for optimal continence or management of incontinence in line with personal preference;
- bladder and bowel signs and symptoms that warrant further attention;
- socio-cultural and environmental factors contributing to incontinence; and
- targeted and individualised continence care.

Incorporating consumer choice, values and goals is vital to ensuring their dignity is maintained. Valuing an individual's right to dignity in care is essential to ensuring person-centred and safe and effective care for people accessing aged care services. It must be at the core of values that help to determine how care is provided, maintained and evaluated in a cohesive manner for consumers, families or proxies (individuals with decision-making capacity) and carers.

Appropriate person-centred care should always place the person living with incontinence at the centre. Incontinence can occur for a variety of reasons, meaning that both cause and treatment are individual in nature. Addressing such issues therefore requires taking into account the personal beliefs, goals and preferences of those affected by incontinence throughout the process. Practices that are perceived as dignified for one person may be perceived as a violation by another. Culture, language and life experience create a defined boundary around practices including screening, assessments, interventions and care provision. When carers acknowledge and act on these preferences, care-dependent people feel safe, respected, and dignified as individuals. The promotion of wellbeing and safety at all times means that choice, control and independence are maximised while promoting communication between consumers, families and care workers to ensure the best possible outcome.[27]

Quality and safety in aged care

The *Quality of Care Principles 2014*[28] that were in effect until 30 June 2019 detailed the responsibilities of approved providers of aged care services. Regarding residential care services, the expected outcome of Standard 2.12 (Health and Personal Care) states: *Care recipients' continence is managed effectively*. Nevertheless, the proportions of complaints to the Aged Care Complaints Commission, and later the Aged Care Quality and Safety Commission (ACQSC) regarding continence management have been consistently substantial.

- In 2014–15, the most common issue recorded in complaints across all types of aged care related to health and personal care (28.8%) which included issues associated with continence management and personal hygiene.[29]
- In 2015–16, complaints about continence management in residential aged care were the third most common issue, and complaints about the choice and dignity of the person receiving care the fourth most common issue.[30]
- In 2016–17, continence management was in the top five concerns most commonly referred to the Aged Care Complaints Commission.[31]
- In the last quarter of 2018–19, formal complaints to the ACQSC showed that, for residential aged care, continence management ranked in the top five most common issues subject to complaint.[32]

New Aged Care Quality Standards

New Aged Care Quality Standards[33], with dignity, choice and person-centred care as central tenets, came into effect on 1 July 2019 with guidance and resources to support their implementation. Good care will improve residents' dignity, quality of life, and mental and physical health. Respecting residents' dignity is a key element in continence care and the management of incontinence. However, there may be a mismatch between residents' and their families' expectations of care and management which dignifies them and that of their carers.

From 1 July 2019, the *Aged Care Legislation Amendment (Quality Indicator Program) Principles 2019*[34] took effect and the National Aged Care Quality Indicator Program is now mandatory for all Commonwealth-subsidised residential aged care services. The Program requires services to collect data on every consumer each quarter, against the following clinical quality indicators:

- pressure injuries;
- use of physical restraint; and
- unplanned weight loss.

Skin injuries that result from incontinence-associated dermatitis and pressure injuries may present in the same way as pressure injuries that result from *localized damage to the skin and underlying soft tissue usually over a bony prominence or related to a medical or other device* (the definition used in the National Aged Care Mandatory Quality Indicator Program Manual 1.0).[35] However, it appears that skin damage linked to incontinence-associated dermatitis is specifically excluded from this definition of pressure injury:

> *This stage should not be used to describe moisture-associated skin damage (MASD) including incontinence-associated dermatitis (IAD), intertriginous dermatitis (ITD), medical adhesive-related skin injury (MARSI), or traumatic wounds (skin tears, burns, abrasions).*

The obvious concern is that the National Aged Care Mandatory Quality Indicator Program includes no measurable quality indicator which will detect unsafe and ineffective continence care. It is clear that such a quality indicator needs to be developed.

Individualised, person-centred continence care plans are crucial

Individualised continence care plans are necessary to ensure safe and effective care. A recent study in the United States revealed that of the 48% of nursing home residents who had urinary incontinence, only 54% had a care plan for their incontinence. For those with a urinary incontinence care plan, only 35% had a person-centred urinary incontinence care plan developed based on that resident's voiding pattern and needs.[36]

There is no similar information available for Australian RACFs, but we can judge whether individualised continence care plans are valued by looking at whether they are documented in the accreditation reports of Australian RACFs. Ostaszkiewicz et al.[37] audited accreditation reports to determine which descriptors were used to report on the quality of continence care. All facilities had met Accreditation Standard 2.12 (Health and Personal Care): *Residents' continence is managed effectively*. Most accreditation reports recorded that residents were assessed to identify their continence care needs, but most did not record what care residents preferred, needed and were receiving (Table 1).

Table 1. Factors documented by assessors in RACF accreditation reports.

Factors assessors documented	**Number of statements N=87 (%)**
Residents are assessed to identify their continence care needs	79 (91)
Residents and representatives are satisfied with continence care	73 (84)
The facility has a system or process in place to meet residents' continence care needs	57 (66)
The facility has a stock/supply of continence aids	56 (64)
Residents have individualised bowel management programs	33 (38)
Residents have individualised toileting assistance programs	26 (30)
Staff know residents' individual needs	16 (18)

Source: Ostaszkiewicz J, O'Connell B, Dunning T. How is the quality of continence care determined in Australian residential aged care settings?: a content analysis of accreditation reports. Australian and New Zealand Continence Journal. 2012 Dec 1;18(4):102-6.

Table 1 shows that only 38% of accreditation reports documented whether residents had individualised bowel management programs, and even fewer (30%) documented whether residents had individualised toileting assistance programs. Although these results do not reflect the continence care residents were actually receiving, they do reflect the lack of importance that assessors placed on finding out about the individualised continence care of residents.

Assessors did not consider information regarding individualised continence care plans that reflected residents' preferences as important as whether the facility had a supply of continence aids. This is concerning, because it appears that individualised continence care plans that reflected residents' preferences were not used to determine whether an RACF met Accreditation Standard 2.12.

Continence screening, assessment and reassessment in aged care services

Suitable evidence-based continence assessment resources for screening, assessment and reassessment of continence care and incontinence management should be used for disabled and older Australians accessing all types of aged care services. Moreover, those caring for people in aged care must understand the necessity of using such resources and not rely upon information from product providers regarding the use of containment products (incontinence pads and pants), which could result in passive rather than active management of incontinence.

Staff working in aged care services should have:

- adequate training on the assessment and management of incontinence to be able to conduct a basic assessment of a person's continence status and needs; and
- access to continence assessment tools that support safe and effective continence care and incontinence management.

Additionally, clear decision-making pathways are needed to assist with decisions about interventions and when to make referrals to specialist services. Importantly, all staff should have the capacity to report on incidents of unsafe or inadequate continence practices and/or care.

A continence screening, assessment and reassessment tool has been developed in Australia for Australians. The evidence-based, validated, newly revised and updated *Continence Resources for Aged Care* is a suite of tools developed for the Commonwealth Department of Health.[38] They can be used singly or in combination for screening, full continence assessment and reassessment (as part of a care plan review). The individual resources are listed below:

- Continence Screening Form
- Three Day Bladder Chart
- Seven Day Bowel Chart
- Monthly Bowel Chart
- Bristol Stool Chart
- Continence Assessment Form and Care Plan
- Continence Care Summary
- Continence Resources for Aged Care: User Guide.

The *Continence Resources for Aged Care* are designed to be used by all aged care staff and, importantly, direct those undertaking continence assessments to seek further guidance from a health practitioner (registered nurse or doctor) if there are medical considerations. The health practitioner is then responsible for determining what interventions are required and when to make a referral to a specialist service.

A multidisciplinary approach to safe and effective continence care

While continence care and incontinence management are currently considered a nursing domain and (with nursing oversight) a personal care worker domain, there can be important roles for other members of a multidisciplinary team.

Medication can significantly impair continence, either directly affecting bowel and bladder function or indirectly causing constipation or diarrhoea and diuresis, all of which can precipitate incontinence or contribute to incontinence in a vulnerable individual. Kashyap et al.,[39] showed that community-dwelling, older, incontinent Canadians have a high prevalence of use of medications which can cause urinary symptoms, and that polypharmacy in this group was associated with medication use contributing to incontinence. An association between polypharmacy and incontinence is even more likely in the more vulnerable RACF population. Deprescribing medications potentially contributing to lower urinary tract symptoms and reducing polypharmacy in an already symptomatic group, would be a judicious management priority even before additional assessment is undertaken.

Specialist physiotherapists with continence expertise can assess and prescribe treatment for incontinence; physiotherapists can minimise mobility restrictions; occupational therapists can assist people to overcome environmental barriers and access; and dieticians can support bowel health. All can play a role in community and residential care and should be considered as part of a good practice continence evaluation approach.

Finally, identification of reversible causes for incontinence can improve continence management. Selected cases may benefit from more detailed assessment by a Nurse Continence Specialist[40], a continence physiotherapist, a geriatrician with a specific interest in incontinence, a urologist, a urogynaecologist or a colorectal surgeon.

Unsafe and ineffective continence care in aged care services

According to the new Aged Care Quality Standards (ACQS), **unsafe and ineffective continence care is care that does not:**

- treat consumers with dignity and respect, allowing them to make informed choices to live the life they choose (ACQS 1);
- include ongoing assessment and care planning which optimises health and wellbeing, in partnership with and in accordance with the consumer's needs, goals and preferences (ACQS 2);
- ensure consumers get safe and effective personal and clinical care in accordance with their needs, goals and preferences to optimise their health and wellbeing (ACQS 3); or
- provide the services and supports for daily living that consumers consider important for their health and wellbeing (ACQS 4).[33]

Key to meeting consumer and carer expectations regarding safe and effective continence care is informed choice which is then enacted. A continence assessment collaboratively undertaken by appropriately skilled, trained and educated staff, and utilising additional clinical expertise when required, is necessary to provide the care recipient and their nominated person with knowledge needed to make choices. Therefore, unsafe and ineffective care is care which neither informs nor

offers meaningful and/or effective choice. Such inadequate care may include, but is not limited to any of the following (singly and in any combination):

- a lack of appropriate continence assessment to identify each resident's individual continence care needs and to identify and treat potentially reversible causes of incontinence;
- failure to identify bladder and bowel signs and symptoms that warrant further attention or medical advice;
- a continence care plan that is generic, primarily cost driven, and inconsistently delivered, encouraging disagreement and disempowerment;
- poor assessment not aligned to the individual's preferences or needs;
- the use of incontinence products that do not match residents' individually assessed needs;
- the promotion of incontinence products as a substitute toilet;
- inadequate provision of incontinence products to meet the intended needs;
- infrequent or untimely assistance for residents to reach and use the toilet;
- inadequate staffing numbers to provide physical assistance to residents needing to use the toilet, particularly when lifting machines are required or the resident is not mobile;
- infrequent or untimely assistance to change residents' incontinence products;
- the inappropriate use of, or removal of, indwelling catheters;
- where aids or appliances (e.g. catheters) are inappropriately used and maintained or inappropriately removed or rationed in order to meet budget;
- the over or underuse of laxatives;
- the inappropriate use or overuse of sedatives, psychotropics and opioid analgesics;
- the inappropriate use of physical restraints;
- no attempt to monitor effectiveness or regularly review a continence care plan, especially when there is a change in health status;
- no attempt to minimise incontinence or re-enablement aligned to an individual's preferences;
- diagnostics such as urinalysis or urine culture, in the absence of clinical symptoms, routinely undertaken resulting in unsafe and inappropriate use of antibiotics; and
- no regular medication review or medication reconciliation, with emphasis on reducing iatrogenic harm or untoward side effects, is undertaken at a transition point.

Risk of developing incontinence in aged care settings

Incontinence is prevalent, in all aged care settings, but is particularly high in RACFs and there is evidence that prevalence increases quickly with time spent in an RACF. International research shows that urinary incontinence increases over time in RACFs. A study of people admitted for the first time to RACFs in the United States found that the prevalence of urinary incontinence at two weeks was 37% but increased significantly to 43.8% after one year.[41] Saxer et al.[42] undertook a detailed study of the prevalence and incidence of the development of urinary incontinence in residents in Swiss RACFs. They found that the prevalence of urinary incontinence in women increased from 32% at admission to 42% at six months and 49% at 12 months. For men, the prevalence of urinary incontinence increased from 45% at admission to 48% at six months and 57% at 12 months. The researchers stated that *a specific urinary incontinence assessment at admission is very important to enable early initiation of specific urinary incontinence prevention and therapy*, implying that

continence care was not optimal and may have contributed to the development of incontinence in this population.

Very recent research sought to identify factors which could be used to predict continence decline over two years in institutionalised older people. Jerez-Roig et al.[43] found that, after two years, 38.8% of people in Brazilian RACFs had experienced a decline in their urinary continence status. In Saxer's study[42], 26% of people experienced a decline in their urinary continence status after being admitted to an RACF. Predictors of continence decline included disability and potentially inappropriate medications at baseline and functional decline over the two-year period.

There is no data available on the increase in prevalence of incontinence in Australian RACFs, although it may be able to be derived from data already collected. The continence status of people accessing My Aged Care is determined during an assessment by an ACAT and then when being assessed for ACFI funding and reassessed for ongoing funding.

Practices and policies in RACFs may be contributing to the increased prevalence of urinary incontinence over time, but without a comparison or control group, no definitive conclusions can be reached. Without a comparison group in the community, we do not know whether the increase in incontinence is due to RACF practices and policies or due to a natural decline in health (i.e. the reason for admittance to the facility in the first place).

There is some evidence which shows that relatively short-term admission of older Australians to acute care settings puts them at high risk of developing incontinence. A 2016 Victorian study[44], documented the development of incontinence at time of discharge from hospital for people aged 65 years and over diagnosed with dementia or cognitive impairment, but ambulant and continent pre-admission. It was found that:

- 21% of patients experienced an episode of urinary incontinence during their hospital stay but were continent at discharge;
- an additional 36% developed urinary incontinence and were incontinent at the time of discharge from the hospital; and
- of the 36% with urinary incontinence, 2% also developed faecal incontinence.

The results clearly showed that this group of people, who were continent on admission, were at significant risk of developing incontinence in care. The length of stay also increased the risk of developing incontinence. In order to reduce the risk of hospital inpatients developing incontinence, Furlanetto and Emond[44] recommended the implementation of person-centred care, dementia-friendly design, staff education and the promotion of cultural change.

Consequences of unsafe and ineffective continence care

Incontinence has numerous detrimental effects on physical and mental health and quality of life. Kwong et al.[45] showed urinary incontinence was associated with lower quality of life in community-dwelling older adults. Du Beau et al.[46] found that in RACFs, urinary incontinence was associated with reduced quality of life, even in frail, functionally and cognitively impaired residential aged care residents. Incontinence contributes to social isolation and depression[47] and can be humiliating. Incontinence and its perceived stigma lead many to modify and restrict their activities, including by declining attendance at social events ranging from shared mealtimes to group activities and outings.

Urinary incontinence has been consistently associated with increased falls. Whilst it can be postulated that restricting mobility is safest for some, the concept of dignity of risk and premature reduction in mobility hastening functional decline and dependence needs to be considered and discussed with the care recipient. A toileting program, together with appropriate use of aids such as a urinal or bedside commode may be a suitable option.

Consequences of unsafe and ineffective continence care and incontinence management may include, but not be limited to:

Urinary tract infections (UTIs)

- RACFs: urinary incontinence (and the presence of a urinary catheter) is associated with increased risk of UTIs.[48,49]

Incontinence-associated dermatitis

- Hospital: among patients with incontinence, 20.7% acquired incontinence-associated dermatitis during their hospital stay.[50]
- RACFs: in residents admitted when incontinent, but free of skin damage, skin damage developed after a median of 13 (range 6–42) days in 45 of 981 residents (4.6%); 3.4% was determined to be incontinence-associated dermatitis.[51]

Pressure injuries

- Hospital: among patients with incontinence, 6.3% had a hospital-acquired pressure injury.[50]
- RACFs: faecal and urinary incontinence increase the likelihood of having had a pressure sore.[52]

Pressure injuries not healing

- RACFs: incontinence is associated with pressure ulcers not healing.[53]

Falls

- Community: urinary incontinence is a risk for falls[54], for recurrent falls in older people[55], and the larger the volume of urine lost, the greater the risk of falls.[56]
- RACF: urinary incontinence is associated with frequent falls.[57]

Avoidable emergency department admissions

- RACFs: In residents transferred to emergency departments (EDs), rates of UTIs and hip fractures were higher than for those living in the community who were transferred to the same Australian EDs.[58]

Functional decline

- Community and RACFs: incontinent women are more than twice as likely to experience decline in activities of daily living, including using the toilet on their own.[59]

Depression

- Community: major depression occurred in 44.0% of women with idiopathic urge (±stress) incontinence and in 17.5% of women with stress incontinence.[47]

Quality of life

- RACFs: urinary incontinence is associated with reduced quality of life, even in frail, functionally and cognitively impaired nursing home residents.[5,46]

Recommendation 2

Incontinence should be acknowledged as a cost driver in RACFs and must be funded adequately.

- Funding in any implemented funding/care structure (including the proposed AN-ACC funding model) must acknowledge incontinence as a significant cost driver in RACFs.
- Ensure adequate funding for safe and effective continence promotion, care and incontinence management for all residents in RACFs.

Incontinence is prevalent

Incontinence is one of the top three critical factors identified for older Australians needing to transition from home-based aged care to residential aged care.[10]

Incontinence can also increase the risk of ACAT recommendation to residential care. The *Aged Care Assessment Program National Data Repository Annual Report 2007-2008*[11] set out data relating to ACAT assessment of clients for aged care services. Although these reports are no longer published, they provided valuable insight into the reasons for recommendation for entry into RACFs.

Risk factors for a recommendation for RACF entry were identified. Urinary incontinence and faecal incontinence were found to be in the top four condition-related risk factors influencing recommendations, along with confusion and dementia. All else being equal, faecal incontinence increased the risk of being recommended for residential care by 86%, and urinary incontinence increased the risk of recommendation by 39%. In comparison, a diagnosis of dementia increased the risk of recommendation for residential care by 83%.[11]

International data suggests the prevalence of incontinence in RACFs is 60–90%.[9] People living permanently in RACFs are more likely to experience incontinence. As noted earlier, in Australia in 2010, 128,473 residents or 70.9% of residents in aged care facilities had urinary or faecal incontinence or both, and their number is projected to increase to 253,113 by 2030. More recent data confirms that incontinence is highly prevalent within the aged care sector, with 75–81% of people in RACFs living with the condition.[8] Just over half of residents (54%) experienced more than three episodes daily of urinary incontinence or passing of urine during scheduled toileting, and 34.8% experienced more than 4 episodes per week of faecal incontinence or passing faeces during scheduled toileting.[7]

Incontinence is a major cost driver in RACFs

As part of the National Continence Management Strategy (1998–2010), a *Framework for Economic and Cost Evaluation for Continence Conditions* was developed.[60] It involved measurement of the direct costs of continence care and incontinence management in RACFs, including staff and consumables costs. Using this data, Deloitte Access Economics[7] determined that daily costs amounted to $34.96 per person or $12,760 per year. In 2008–09, $1.3 billion (30% of the total residential aged care government subsidy) was used for people who needed assistance with both incontinence and toileting in RACFs.[61] Cost, however, should not be a barrier to effective continence care and treatment.

The promotion and maintenance of continence and safe and effective management of incontinence is much more than simply taking residents to the toilet and providing incontinence products. Safe and effective continence care and incontinence management can lead to the resolution of the issue, but requires investment. Funding should be continued where safe and effective care leads to resolution of incontinence and where the need for the care is ongoing – for example, when more frequent scheduled toileting and/or assisted toileting may resolve accidental soiling or wetting, but must be ongoing for the results to be maintained.

Continence care, done well, should generate savings in the longer term by reducing costs associated with incontinence products, UTIs, incontinence-associated dermatitis and pressure injuries, and the extra costs associated with their treatment. Additionally, effective care plans and treatment will reduce costs because the effectiveness of staff time will be maximised, the use of expensive incontinence aids will be reduced and the level of independence of residents may be improved.

Toileting assistance must form part of safe and effective continence care

Managed or 'social' continence is an attainable goal for everyone and a basic right.[62] No person who is capable of using a toilet, and who wishes to do so, should suffer the indignity of being expected to use containment as an alternative to assisted toileting. Containment is a necessary and useful tool, and a safeguard against failures of effective management, but should never be seen as an alternative to effective management and treatment, when feasible.

Active promotion of continence care and incontinence management, including toileting assistance and/or prompted voiding, have been shown to significantly reduce episodes of incontinence, but are more labour intensive than passive containment strategies. In the United States, Schnelle et al.[63] quantified the level of staffing required to optimise the continence of residents in an aged care facility. The Functional Incidental Training intervention was trialled and compared with standard care. The time taken to implement the intervention, **which improved functional status and reduced incontinence episodes**, was calculated. It was determined that one staff member was required for every five residents to implement the intervention successfully.[64]

The obvious concern is that because providing toileting assistance is more labour intensive and costly than checking and changing residents' incontinence products, the passive management of incontinence (using incontinence products) rather than active management (such as toileting assistance) would be further incentivised. When determining the value of the intervention, rather than just the cost, Schnelle et al.[63] asked a proxy group of residents to make choices between the intervention and its associated outcomes (e.g. increased dryness) and other services of known cost (e.g. moving to a private room). Overwhelmingly, residents preferred the Functional Incidental Training intervention (which included 15 minutes of exercise, verbal interaction, dryness and walking improvements) to moving from a shared to a private room. Clearly, residents valued person-centred care, which involved active management of incontinence, highly.

In summary, effective continence care, particularly with a restorative and re-enablement component as in the example above, may seem costly, but it should generate savings in the long term.

Dementia reduces awareness of incontinence

In 2018-19, half (51%) of the residents in Australian RACFs, with an ACFI assessment, had a diagnosis of dementia.[12] Earlier data revealed that residents with dementia had high levels of need for assistance with toileting and continence care. In 2008–09, 67% of residents with dementia required physical assistance with toileting and 73% required physical assistance with toilet completion. Seventy-four percent of residents with a diagnosis of dementia had a higher level of dependency for continence than other residents (48%); 69% of residents with dementia had three or more episodes of urinary incontinence daily or scheduled toileting; and 46% had four or more faecal incontinence episodes a week or scheduled toileting.[14]

It can be more difficult to provide continence care for people with dementia because the condition may affect their awareness of their bladder and bowel needs. Anecdotal evidence suggests that many residents in Australian RACFs have undiagnosed cognitive impairment, with the true rate of possible/probable dementia closer to 70% (Michael Murray, geriatrician, personal communication, 2019). Although some of these individuals will be at the lower end of disease severity, some will not, and all will progress. The success of in-home community care means any person transitioning to residential care is doing so due to unmet or unacheivable needs. Transitioning residents will have significantly greater needs, with incontinence previously identified as a final precipitant for many transitions to residential aged care. The ageing population means that more residents of RACFs will have continence needs or dependency in future.

Inadequate funding of continence care in RACFs

Current funding model: Aged Care Funding Instrument (ACFI)

Currently, as part of the ACFI Activities of Daily Living assessment, users are prompted to identify residents' toileting needs and to indicate whether the resident can self-manage or requires supervision and the degree or level of assistance required. Additionally, the ACFI prompts users to identify the frequency of residents' urinary and faecal incontinence.[65] The ACFI also asks users to measure incontinence-related conditions including skin integrity, suppositories and enemas, catheter care and ongoing stoma care which require qualitative assessment and/or diagnosis with corresponding directives of care.

Although the ACFI is very limited in terms of the number of questions about residents' continence status, it nevertheless has a greater focus on continence issues in both direct and indirect measurements than the Australian National Aged Care Classification (AN-ACC) assessment tools used in the proposed funding model (see below).

Proposed AN-ACC funding assessment model is inadequate for incontinence

Although the separation of funding assessment from care planning assessment in RACFs has real merit, the capacity of the proposed new funding model to evaluate incontinence is weak and does not provide an accurate picture of the complex needs of aged care facility residents. The proposed AN-ACC funding assessment model[66] lacks a comprehensive continence assessment tool and relies purely on an assessment of mobility and the need for assistance to use the toilet. Although important, these are not the sum total of good continence management. Without a comprehensive assessment tool at the funding stage, appropriate continence care and incontinence management will not be adequately assessed or funded, and care planning will worsen. Adequate funding must be

provided to ensure safe and effective, proactive continence care. A lack of funding will result in continence care and incontinence management strategies limited to containment and help with toileting (if, or when, staff are available and understand the importance of toileting).

Containment rather than promotion of continence

Studies conducted worldwide including Australia, across all care settings (home care, acute care and long-term care), reveal that containment interventions are often provided to older people rather than strategies for the promotion of continence.[67-71] Containment is the use of, or overreliance on, incontinence pads to contain urine or faeces after episodes of incontinence. Containment is a cheap and minimalist model of care which may not consider people's rights to have their preferences actioned, such as help to use the toilet and the use of other aids such as urinals and bedside commodes. Containment does not promote continence, although it may be a useful strategy in management (when the smallest, most suitable aid is used) and as a bridging technique while efforts to improve a person's incontinence are underway.

In response to concerns about potential complaints or a failed accreditation, many RACF staff equate effective continence care with containment (incontinence pad use).[16] Containment strategies are often used in response to limited time and competing clinical priorities when providing care. Importantly, the use of containment aids should always be an informed personal choice around dignity and quality of life and form part of a toileting strategy backed by a documented continence assessment.

Australian studies on this topic are scarce, but what has been documented is telling. Firstly, the bladder and bowel function of older Australians is not being consistently assessed and/or documented when they are admitted into acute and subacute care and secondly, they are often expected to use incontinence products, even when they are continent. Ostaszkiewicz et al.[69] surveyed patients with an average age of 70 (± 18.7) years admitted to four Australian hospitals. They found that 60% were using a continence product or device, but of these 41% had had no episode of incontinence in the preceding 24 hours. Ostaszkiewicz et al.[69] characterised management of incontinence in the hospital setting as suboptimal and called for greater clinical awareness of incontinence in hospital settings, and a systematic approach to its assessment and management, allowing incontinence symptoms to be identified and appropriately addressed by staff.

A more recent Australian study[50] of 250 adult patients, with an average age of 73 (± 17) years, in 12 units across four Sydney hospitals found that:

- no patients had a continence management program;
- there was an emphasis on incontinence products and devices, indicating a passive approach by staff to managing the risk of incontinence, rather than a scheduled toileting regimen; and
- 22% of patients who were continent were wearing an incontinence product and when asked about this, nurses stated that it was 'just in case' or 'better to be safe'.

Barakat-Johnson et al.[50] described incontinence management in the hospitals as inconsistent with evidence-based research and reflecting a passive approach to the risk of incontinence, with an emphasis on incontinence products rather than active management such as providing toileting assistance. They highlighted that many factors may influence nurses' preference for using

incontinence pads, including staffing levels, lack of awareness, inadequate assessment of patients and inadequate education in this area.

The Foundation argues that containment should not be implemented as a substitute for deficient staff assessment and implementation skills or staff availability on the part of a hospital or RACF. The potential harms of inappropriate continence care and management are too great to dismiss.

Use of incontinence pads for continence care

Incontinence products, including pads, play an important role in the management of incontinence. Suitable incontinence products are critical for the quality of life and mental and physical wellbeing of product users and their caregivers. Successful concealment enables people with incontinence to protect their public identity as a "continent person" and avoid the stigma of incontinence. The stigmatisation of incontinence can lead to withdrawal from work, social, physical and sexual activities and concealment of their incontinence that adds to psychological distress[15] and mental health issues.[72,73]

The selection and use of a particular product can vary between consumers even for a somewhat similar condition. Assessment and personal experience confirm what user groups have long said: *access to a range of products to test will help determine the most satisfactory choice. Similarly, priorities vary between users; for example, some will opt for a bulky, less discreet pad to achieve an acceptably low risk of leakage while others will see the balance differently*.[74]

It is almost certainly true that incontinence pads are overused, with an excessive focus on containment at the expense of implementing strategies to improve and maintain an individual's independence. Incontinence pads and other containment strategies have an important role in management and as a bridging technique whilst undertaking efforts to reduce risk factors that rob individuals of their independence and contribute to their incontinence. Assuming one has awareness of the need to void or defecate, poor mobility and dependency in transfers and garment manipulation (pants up, pants down) are the greatest risk factors for incontinence. They should be the focus for re-enablement, both in general and when continence has deteriorated after an illness or exacerbated by a necessary change in circumstances (e.g. a change in medication).

There will be times when – and individuals for whom – containment is a very appropriate choice. Cognition, mobility and function which cannot be safely or successfully significantly improved or informed personal choice may support the use of products such as pads, all or some of the time (e.g. overnight when transferring is too distressing or one's ability to defer is so limited as to make any toileting program largely ineffective). The use of containment aids should be an informed personal choice around dignity and quality of life, and acceptance of the dignity of risk, and form part of a toileting strategy backed by a documented continence assessment.[75] Operationalising the balance between personal autonomy and risk of falls can be challenging. Containment, together with other active interventions such as a staff-supported toileting program, could be discussed in the development of a person-centred care plan.

Recommendation 3

Continence education must be a mandatory requirement for all health professionals and personal care workers who work with disabled and older Australians accessing aged care services.

- All staff and health professionals who provide care and treatment including, but not limited to, personal care workers, enrolled nurses, registered nurses, nurse practitioners, therapists, general practitioners and geriatricians in aged care services must (1) receive education about safe and effective continence care and incontinence management in their foundation courses (VET and undergraduate courses) and (2) have regular, ongoing professional development and training in continence management.
- Review of the content of the qualification for personal care workers [Certificate III in Care Support (Ageing)], who provide most continence care, must recognise the need to build capacity in continence care (which, at present, it does not).

Education of the aged care workforce

The aged care workforce is largely untrained in safe and effective continence care and incontinence management. All staff should receive education about safe and effective continence care and incontinence management in their vocational education and training (VET) or undergraduate courses.

All health and medical professionals and care workers will care for people with incontinence, particularly those caring for older Australians and those living with a disability in both the community and in RACFs. However, the aged care services workforce is significantly under-skilled in safe and effective continence care. In Australia in 2016, an estimated:

- 366,027 people worked in aged care, with 240,317 in direct care roles[76] – most of whom are unlikely to have had an appropriate level of continence training or education;
- 70% of direct residential workers were personal care workers[76] – unlikely to receive training in continence care and incontinence management[77], but providing most care;
- 15% of direct residential workers were registered nurses and 10% were enrolled nurses[76] – neither adequately prepared to provide good continence care and incontinence management;[78-80] and
- 84% of home care and home support direct care workers were community care workers, followed by registered nurses (8%).[76]

Personal care workers and enrolled nurses

Personal care workers make up most of the workforce in aged care services, they provide most direct continence care, but receive the least training. The qualification that VET-trained personal care workers now hold is CHC33015 – Certificate III in Individual Support, which includes no specific education about continence care.[77] Based on a review of core units designed to prepare trainees to work with older people or care-dependent people, it is highly unlikely they will be sufficiently equipped to provide safe and effective continence care.

Enrolled nurses also have direct responsibilities for continence care in the aged care sector. Most VET-trained enrolled nurses hold the Diploma of Nursing (HLT54115 - Diploma of Nursing) which

includes no specific education or training in continence care.[79] Some enrolled nurses who hold the Advanced Diploma of Nursing (HLT64115 - Advanced Diploma of Nursing) can choose to do one elective unit of competency which may cover continence. HLTENN017 – Apply Nursing Practice in the Rehabilitation Care Setting expects trainees to have knowledge of genitourinary disorders and gastrointestinal disorders, which may include urinary and faecal incontinence.[80] Enrolled nurses are unlikely to have sufficient knowledge and skills to provide safe and effective continence care.

Recent Australian research revealed that RACF staff view incontinence as a risk to the cleanliness of residents, their social status and their dignity[16], and respond by pursuing strategies that conceal, contain and control signs of incontinence to protect (in their eyes) the dignity and wellbeing of residents. However, the concept of dignity often does not align in residents' and care workers' beliefs.[27] Quality of care can be skewed by multiple factors, including a lack of continence-related education and pervasive beliefs about incontinence being inevitable.[17] This may lead to practices of concealment with pads rather than long-term management strategies or treatment. These subjective notions of dignity in practice must be addressed to ensure targeted, individualised and person-centred care is delivered.

Education of the front-line aged care workforce needs to address this lack of understanding about incontinence and improve practices to ensure person-centred care, which is safe, effective and consistent with the consumer's expectation of dignified care.

Australian government VET training for personal care workers

In response to recommendations from the Aged Care Workforce Taskforce (2018) report *A Matter of Care – Australia's Aged Care Workforce Strategy*[81], SkillsIQ, under the direction of the Aged Services Industry Reference Committee, is developing a new qualification – the Certificate III in Care Support (Ageing).[82] This work is *aimed at ensuring workers are equipped with the skills required to work effectively in the aged care sector and provide quality care to their clients.*[83] The new qualification is in the draft stage and recognises the need for personal care workers to be able to provide support to people living with dementia, but appears to have no content in any unit of competency (core or elective) about incontinence prevention, assessment or management.

This review of the content of the qualification for personal care workers, who provide most continence care, must recognise the need to build capacity in continence care. Missing this opportunity will adversely affect Australians receiving aged care services and have a detrimental impact on many facets of their lives.

Registered nurses

There is no recent publicly available information on the depth and coverage of the continence curriculum content in undergraduate nursing courses in Australia. A national review of Australian undergraduate nursing and midwifery courses found that registered nurses were not adequately prepared to provide safe and effective continence care and manage incontinence.[78] To remedy this, after much consultation and research, Paterson created guidelines for integrating education about incontinence and good continence care into undergraduate nursing and midwifery curricula. The guidelines consisted of five core elements that needed to be included in the curricula, and 10 recommendations to enhance the usage of the guidelines. It was determined that the following core elements would facilitate the learning outcomes:

- knowledge and awareness about incontinence, including prevalence, risk factors, definitions and financial cost;
- knowledge about prevention of incontinence and promotion of continence;
- knowledge and assessment skills, including client goals, health history and understanding the reasons behind and types of incontinence;
- clinical reasoning to identify those at risk, knowledge of referral processes and evaluation of continence management programs; and
- development of a care plan based on the best evidence available.

This work was undertaken, under the National Continence Management Strategy and was published in 2006[78] but was not acted upon. As a result of this missed opportunity, more Australians receiving aged care services have been disadvantaged.

The recently released *Educating the nurse of the future – Report of the independent review of nursing education*[84] reviews the educational preparation of nurses in Australia. The Foundation made a submission to the review of nursing education to stress the need for education about incontinence and safe and effective continence care to be included in the foundation courses for enrolled and registered nurses. Subsequently, Professor Schwartz's report **recommended that incontinence be included in the nursing curriculum** because it was *not uncommon in hospital, aged care and other health setting**s*** **and recommended both enrolled nurses and registered nurses be introduced to the basics of continence care.** This is a clear acknowledgment that current course curricula are inadequate in relation to continence care.

Nurse Continence Specialists

Until recently, Australian registered nurses who wanted to specialise as Nurse Continence Specialists had the option of undertaking postgraduate courses, specifically the:

- Graduate Diploma in Nursing (Continence Nurse Advisor) at Flinders University, and
- Graduate Certificate in Urology and Continence at La Trobe University.

These courses are no longer available, and there is little scope for registered nurses to gain the necessary specialised knowledge required to become competent Nurse Continence Specialists. At the time of writing this submission, the only course offered at this level for nurses wanting to increase their continence knowledge is a single unit of study, Continence Management, offered by the Australian College of Nursing.[85]

The lack of educational opportunities for registered nurses to specialise in continence care is a serious gap for the continence care workforce. The role of the Nurse Continence Specialist should be understood and valued, but it is not, and moreover is threatened by:

- job losses or cuts to positions that had already occurred or were feared would occur;
- National Disability Insurance Scheme (NDIS) actually or potentially causing job losses;
- downgrading of positions from Nurse Continence Specialist roles to generalist registered nursing roles, but relying heavily on continence skills;
- workplaces undergoing reviews or restructures with concerns this will result in loss of, or downgrading of positions, and
- use of nursing staff without continence qualifications or from other disciplines in what were previously designated continence nurse advisor roles[86].

Although the role of Nurse Continence Specialist should be valued and protected and promoted, until it is, the need for enrolled and registered nurses to have fundamental and adequate knowledge of continence care and incontinence management is even more of an imperative.

Nurse practitioners

Nurse practitioners are registered nurses who are experienced in their clinical specialty, hold a Masters degree and are endorsed by the Nurses and Midwives Board of Australia to provide patient care in an advanced and extended clinical role. Their training allows them to:

- perform advanced health assessments;
- initiate and interpret diagnostic investigations, such as pathology and diagnostic imaging;
- diagnose health problems;
- design, implement and monitor therapeutic regimens in collaboration with patients, families/carers and other health professionals;
- prescribe medications; and
- initiate and receive appropriate referrals to and from other health professionals.

Nurse practitioners have a unique role in the healthcare system. Their advanced nursing knowledge and expanded skills can meet the service demands and address gaps in existing health care services by providing services where none currently exist, particularly in rural and remote areas.

Nurse practitioners, with the appropriate clinical experience, can and do provide safe and effective continence care to people accessing aged care services. In Australia, nurse practitioners' services in the aged care setting were evaluated and shown to provide *a high quality of holistic nursing care and positively affect clients' physical and psychological symptom management, enhance clients' quality of life, assist with supplies, provide health education and assist with advocacy*.[87] In this study, most presenting problems related to urinary incontinence and bowel management.

Industry

Manufacturers of incontinence products are currently filling the gap in education for staff in aged care services in Australia. The details of continence education and training courses/programs run by industry are not public. However, there is a concern that incontinence product manufacturers being the sole providers of continence courses/programs is a conflict of interest. There is a high risk the information provided may be inadequate, biased and may focus on 'pragmatic' cost-effective management (mindful of staffing resources and assessment and minimal management skills), resulting in residents wearing incontinence pads, rather than incentivising improvement.

Continence Foundation of Australia online resources and courses

For aged care staff to remain competent and current in continence care and incontinence management, they must undertake ongoing training and professional development. And, if there are gaps in their knowledge and skills, they need to be able to readily access reliable, evidence-based information.

There are independent, evidence-based, best practice guides, resources and, training and education opportunities, available to provide on-the-job support, ongoing training and professional development. The Continence Foundation of Australia, in partnership with the Australian Government Department of Health, has developed and continues to develop such supports for aged care staff. These include:

Online resources

The *Continence Support Now* application is an online pocket guide for disability and aged care workers providing bladder and bowel support (see continencesupportnow.com). This application was developed following consultation with representatives from Australian aged care organisations, peak aged care bodies, personal care workers, providers of short course training, the disability sector and Foundation members. The *Continence Support Now* application is designed to provide readily accessible information on continence care and incontinence management to personal care workers and disability support workers. Benefits of the application include *a Just-In-Time* feature which provides immediate information; accessibility for remote and rural workers and support for independent care provision.

Continence Resources for Aged Care, a continence screening, assessment and reassessment tool developed in Australia for older Australians. The evidence-based, validated, newly-revised and updated *Continence Resources for Aged Care* are a suite of tools which were developed for the Australian Government Department of Health.[38] The *Continence Resources for Aged Care* are designed to be used by all aged care staff and, importantly, direct those undertaking continence assessments to seek further guidance from a health practitioner (registered nurse or doctor) if there are medical considerations. The health practitioner is then responsible for determining what interventions are required and when to make a referral to a specialist service.

Online courses – continencelearning.com

Recognising the absence of continence-related training and education, the Foundation has begun development of a four-tiered, online learning program designed to provide basic knowledge of anatomy, physiology, the prevalence of incontinence and identification of continence care needs. The online learning program will build on the current capacity of the workforce with topic-specific learning modules from personal care worker level through to registered nurse level.

The open access *Everyday Continence Care Course* provides the basics of everyday continence care and builds on from *Continence Support Now*. The *Essentials of Continence Course*, in turn, builds on the knowledge gained in the *Everyday Continence Care Course* and provides vital knowledge for the delivery of effective continence care. However, the Foundation recognises that this online learning offering will not completely address skills development relevant to the sector and is exploring a range of initiatives that could help meet this skills gap.

The Foundation has also developed a series of webinars on topics related to continence care in aged care services which include valuable information for all health professionals working with older Australians. Webinar content includes information to upskill health professionals on:

- Continence assessment in the aged care residential setting;
- Dementia and incontinence;
- Aged care in the rural and remote setting;
- UTIs and catheters in the residential aged care setting; and
- Incontinence in frail older Australians with comorbidities in the residential aged care setting.

The need for a safe and effective model of continence care

Incontinence is a condition which can often be better managed and for some, improved significantly. All too frequently it is considered a normal part of ageing and, consequently, is not prioritised nor well understood in aged care. Provision of continence aids may be necessary, and important, but does not constitute good continence care. It is the responsibility of those caring for the continence needs of disabled or older Australians living in both the community and RACFs to strive to maximise their dignity, quality of life and mental and physical health. Safe and effective continence care should be based on people's preferences as well as needs, with their dignity maintained and choice optimised. This is what the Australian Aged Care Quality Agency intends with the development of the new Aged Care Quality Standards.

Australia needs to develop its own model of safe and effective continence care. Such a model should include critical elements that guide those providing aged care services and those assessing whether service providers are meeting the new Aged Care Quality Standards.

To account for personal preferences (informed choice) and maximise dignity, critical elements of a proposed safe and effective model of continence care should include, but not be limited to:

- adequate funding of continence promotion and care and incontinence management within aged care services which extends beyond passive management;
- respectful, qualified assessment of peoples' continence care needs, using high-quality continence assessment resources (not linked to a funding instrument and not provided by/and or linked to a product provider) and regular reassessment or reassessment after a change or decline;
- development of continence care plans which consider personal preferences, include toileting assistance, maximise mobility, and include reablement;
- suitably qualified and educated staff to support the implementation of continence care and incontinence management plans; and
- a monitoring system based on an agreed, measurable continence quality indicator, and key performance indicators for aged care services (already developed[75]).

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