

Submission to the NDIS Annual Price Review 2020-21 consultation

This is a joint submission by the Continenence Foundation of Australia, the Continenence Foundation of Australia in NSW Inc, the Continenence Foundation of Australia Victorian Branch Inc and the Continenence Nurses Society Australia (CoNSA).

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The Continence Foundation of Australia

The Continence Foundation of Australia (the Foundation) is the national peak organisation whose mission is to represent Australians with, or at risk of, incontinence, their carers and health professionals who treat and assist people with incontinence.

The Foundation develops and delivers a range of initiatives in partnership with the Australian government as part of the Bladder Bowel Collaborative and broader National Continence Program. The National Continence Program aims to improve awareness, prevention and management of incontinence for Australians living with incontinence and their carers to be able to live and participate in the community with confidence and dignity. This, in combination with the National Continence Helpline, Continence Foundation of Australia website (continence.org.au) and the *Bladder and bowel* webpages on the Australian Government Department of Health website (health.gov.au) ensures that the general public are able to access information and support related to bladder and bowel health via a number of channels.

The Foundation plays a key role in implementing the National Continence Program Action Plan, the objectives of which include increasing the knowledge of bladder and bowel health and incontinence management for health professionals and care workers by improving access to workforce training, education and support.

The Foundation's membership broadly represents the continence sector and workforce who both provide care and services for, and raise awareness and advocate, on behalf of Australians with, bladder and bowel control problems, including those accessing aged care services.

Continence Nurses Society Australia (CoNSA)

Continence Nurses Society Australia Inc is a non-profit national professional interest group of nurses and midwives who have specialist knowledge and skills in continence assessment and management. CoNSA acts as a national professional voice for all nurse members of the State and Territory continence nursing bodies.

CoNSA members work in diverse roles, in remote, rural, regional and metropolitan areas of Australia to provide specialist advice to individuals with incontinence and bladder and bowel dysfunction across the lifespan. CoNSA members offer expertise across a range of different health settings and specialist areas, including but not limited to: women's health (i.e. gynaecology, midwifery), men's health (i.e. urology), paediatric health, community care, aged care, acute care, rehabilitation (i.e. spinal cord injury), disability etc.

Most of CoNSA's members are Nurse Continence Specialists (a term used internationally and now being adopted in Australia) and are employed as either Clinical Nurse Specialists or Clinical Nurse Consultants and hold a range of post graduate qualifications. The role of CNC is recognised by the Nursing and Midwifery Board of Australia as a nurse who is working at an advanced practice level, which is usually accompanied by a high degree of professional autonomy.

The Contenance Foundation of Australia, the Contenance Foundation of Australia in NSW Inc, the Contenance Foundation of Australia Victorian Branch Inc and the Contenance Nurses Society Australia (CoNSA) are making this joint submission because of grave concerns that safe and effective continence care and incontinence management, for people with disability, are being compromised.

Australia has ratified the *Convention on the Rights of Persons with Disabilities*¹. The Convention acknowledges that the right to social protection and the right to the highest attainable standards of health are fundamental human rights. These are not ideals, these are a series of high-level expectations that should underpin the functioning of a society, that cares for its most vulnerable citizens, particularly people with disability.

Safe and effective continence care, that promotes choice and dignity and results in the highest possible standards of health, is a fundamental human right.

A National Disability Insurance Scheme, that provides equity of access to disability supports, must ensure that disabled people with incontinence, or at risk of developing incontinence, have access to the best possible care. For the NDIS to be sustainable, service providers need to be confident that pricing structures are designed to enable them to provide high quality care, tailored to participants' needs while ensuring the long-term viability of the service provider. We are concerned about growing service gaps leading to a lack of accessibility to best-practice continence care and incontinence management, by people with disability, due to:

- a lack of understanding of the specialised skill set of Nurse Continence Specialists (employed as Clinical Nurse Specialists, Clinical Nurse Consultants or Continence Nurse Advisors),
- NDIS fees for service that expert nurses can claim are not commensurate with their experience/classification and lower than the NDIS fee for service for allied health therapists providing an expert service,
- a lack of appropriately skilled Nurse Continence Specialists in non-metropolitan, rural and remote areas,
- travel funding arrangements being limited and sit in individual plans, making it difficult to fund travel to NDIS participants living remotely.

Recommendations

In order to ensure that people with disability receive safe, effective and sustainable continence care, we make the following recommendations:

Recommendation 1

The fee for service for an expert nurse working at the level of a Clinical Nurse Consultant, providing a continence assessment, should be the same as the fee for service for an allied health professional (episodic therapy rate).

Recommendation 2

Improve accessibility to continence services by NDIS participants in non-metropolitan and rural and remote areas by:

- Increasing the amount of travel that can be billed for delivering services to participants who live outside of metropolitan centres.

- Having a higher fee for service in areas that are currently poorly serviced, such as the Northern Territory and South Australia, to encourage more providers to deliver services to NDIS participants in these areas.
- Providing a process to centralise referrals so that regional and remote services are not disadvantaged by ad hoc request processes for continence assessments.

Evidence for Recommendation 1

The Nurse Continence Specialist

The expertise of the Nurse Continence Specialist and the complexity of the continence assessments they undertake for people with disability is not well understood. Nurse Continence Specialists must have a broad range of knowledge and experience in various aspects of continence care and incontinence management. In their work with children and adults with disability, they must be highly knowledgeable in many areas including neurological conditions, all physical disabilities, developmental disabilities, spinal cord injury, the Autism spectrum and mental health. The assessment, diagnosis and development of varied and individual management plans require Nurse Continence Specialists to be highly skilled. Additionally, they must keep informed about the latest trends in treatment and available products.

As defined in the CoNSA Standards for Practice for Nurse Continence Specialists, a Nurse Continence Specialist is *a Registered Nurse (who may also be a Midwife) who has specialist knowledge and skills in continence care and provides services that are an integral part of an interdisciplinary approach to care of people with bladder, bowel and pelvic floor muscle dysfunction.*² The Practice Standards were developed to define and guide the practice of the Nurse Continence Specialist throughout Australia and describe continence nursing practice in parallel with Registered Nurse Standards for Practice³.

A Nurse Continence Specialist is critical to ensuring best-practice continence care and management of incontinence. Wagg and colleagues⁴ reported on a systematic review, evidence synthesis and expert consensus focused on an internationally applicable service specification for continence care that *'Initial assessment and treatment may be optimally enacted by a dedicated local nurse-led continence service. Nurses with appropriate training are capable of managing and treating incontinence more effectively than primary care physicians. They are also able to triage and independently manage a significant proportion of patients. There is evidence that patients appreciate the communication skills and comprehensive continence care provided by nurses'*.

In Australia, major workforce issues have been identified by Nurse Continence Specialists:

- job losses or cuts to positions that had already occurred or were feared would occur,
- the NDIS actually or potentially causing job losses,
- downgrading of positions that have occurred with positions being changed from Nurse Continence Specialist roles to generalist Registered Nurse roles, but still reliant 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 other disciplines that were previously continence nurse advisor roles⁵.

The case for assessment by a qualified continence expert

Incontinence is a common consequence of acquired brain injury. As many as 85.9% of people with acquired brain injuries from traumatic causes complain of urinary symptoms⁶ and up to 68% report faecal incontinence⁷. Incontinence greatly increases the cost of care for people with an acquired brain injury. 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, improve their quality of life and reduce the cost of their care. The study: *Continence and brain injury: Improving independence and quality of life, and reducing cost of care* was funded by the Insurance Commission of Western Australia Continence and conducted in community-based, injury rehabilitation facilities of the Brightwater Care Group in Western Australia⁸.

During the study, a continence management plan was made by a qualified continence expert following a comprehensive continence assessment and recommendations made that included the use of assistive products. 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, reduce costs and increase independence. The following were the key findings:

- Reduced toileting care hours by 4.3 hours per study participant per week, which represented a reduction in average weekly care costs of \$633.29 per person.
- Reduced average daily costs of consumable products for continence (e.g., continence pads) by \$9.91 per person per day.
- Improved participant independence in activities of daily living, three months after implementation⁸.

The value of a comprehensive continence assessment by a qualified continence expert in reducing costs and increasing independence has been clearly demonstrated. This finding led to the recommendation that service providers' *should ensure a comprehensive continence assessment is completed by a qualified continence specialist*⁸.

The *Rehabilitation following acquired brain injury: National clinical guidelines* developed by the British Society of Rehabilitation Medicine and the Royal College of Physicians⁹ recommend that patients who have continuing urinary continence problems should have assessment by a professional trained in continence management in the context of acquired brain injury

The current UK *National clinical guideline for stroke* developed by the Royal College of Physicians Intercollegiate Stroke Working Party¹⁰ recommends that people with continued continence problems on transfer of care from hospital should receive follow-up with specialist continence services in the community.

Inequity between NDIS fees for service for expert nurse classifications and allied health therapists

There is an inequity in the NDIS Price Guide for services provided by Nurse Continence Specialists and allied health therapists. NDIS fees for services delivered by Nurse Continence Specialists are not commensurate with fees for similar services provided by allied health therapists, such as occupational therapy and physiotherapy.

The expertise of Nurse Continence Specialists is not well-recognised. Nurse Continence Specialists understand the effect of medications, fluid, diet, physical restrictions, surgery, comorbidities and physiology on continence. In addition, Continence Nurse Specialists are required to have a working knowledge of a huge range of containment and assistive products to manage incontinence and promote continence.

The requirements for a Nurse Continence Specialist in assessing and writing a continence care plan and coordinating continence aids/consumables for the consumer is equivalent to an Occupational Therapist in their assessment process for assistive technology. A Nurse Continence Specialist uses a whole-systems assessment process in the same way as an Occupational Therapist assesses functional capacity and needs. Continence assessments and management plan reports should be conducted by Nurse Continence Specialists. Other continence services, such as urinary catheter changes or bowel care, can be conducted by various levels of nursing staff expertise and thus the breakdown of nursing grades in the NDIS price guide can be followed.

There is still an inequity between the fee for service for an allied health professional and an experienced Nurse with post graduate experience. There is no requirement for allied health therapists to have experience nor specialist expertise or training and yet the fees for their services are higher than those for a Nurse providing specialist continence services and working at the level of a Clinical Nurse Consultant.

To ensure the NDIS and continence services provided to participants are equitable and sustainable, this inequity, or gap, between what fees for service can be claimed for Nurse Continence Specialists and allied health therapists, needs to be closed.

Recommendation 1

In order to ensure that people with disability receive safe, effective and sustainable continence care:

- The fee for service for an expert nurse working at the level of a Clinical Nurse Consultant, providing a continence assessment, should be the same as the fee for service for an allied health professional (episodic therapy rate).

Evidence for Recommendation 2

Inequity of access to Nurse Continence Specialists in non-metropolitan Australia

There is a lack of appropriately skilled Nurse Continence Specialists in non-metropolitan areas. The Northern Territory branch of CoNSA has provided information regarding the difficulty in providing continence care and incontinence management for NDIS participants in the Northern Territory. There are two CoNSA members in Alice Springs and three members in Darwin. They have reported that they do not have the capacity to meet the need for NDIS continence assessments. In 2019, they

were experiencing great difficulties in providing services to NDIS participants in the Northern Territory due to their very large workload of non-NDIS clients and the long-distance travel required. They also cited 'a lack of qualified assessors' and 'no other continence nurse to provide assessments in Alice Springs'.

In order to ensure equity of access to continence assessments and ensure that continence management plans are conducted by Nurse Continence Specialists, in a timely manner in non-metropolitan areas, mechanisms need to be incorporated into the NDIS price guide. There is already a precedent for this. A higher fee for remote and isolated service provision exists in the NDIS pricing guide and allied health professionals can charge a higher fee for service in some states to encourage service providers to practice in these areas. There needs to be a recognition of the need for additional travel for continence services delivered outside of metropolitan areas and a commensurate increase in the fee for service that can be charged.

Recommendation 2

Improve accessibility to continence services by NDIS participants in non-metropolitan and rural and remote areas by:

- Increasing the amount of travel that can be billed for delivering services to participants who live outside of metropolitan centres.
- Having a higher fee for service in areas that are currently poorly serviced, such as the Northern Territory and South Australia, to encourage more providers to deliver services to NDIS participants in these areas.
- Providing a process to centralise referrals so that regional and remote services are not disadvantaged by ad hoc request processes for continence assessments.

Supporting evidence

Incontinence and disability: prevalence, health and wellbeing, and participation

A higher rate of disability-related incontinence, compared with the general population, has been reported for many conditions for both children and adults (See Appendix 1). Information from the NDIS reveals that, as of September 2019, 34% of NDIS participants had autism¹¹ (see Table E.11 on page 8). The prevalence of incontinence in children with autism (aged 5 to 16 years) is high with 25% experiencing daytime urinary incontinence, 30% experiencing night-time urinary incontinence and 12.5% experiencing faecal incontinence¹².

People with disability experience particular challenges with incontinence issues, with many experiencing severe incontinence. Severe incontinence is defined as someone who always or sometimes needs assistance with managing their bladder and bowel control and/or uses continence aids. In 2012, 1.8% of Australians (or 391,000 people with disability) experienced severe incontinence¹³. This is an increase from 316,500 people in 2009 and 284,500 people in 2003¹⁴.

Table E.11 Participant profile per quarter by disability group - NATIONAL²⁵

Disability	Prior Quarters		2019-20 Q1		Total	
	N	%	N	%	N	%
Autism	85,889	30%	9,062	34%	94,951	30%
Intellectual Disability ²⁶	72,992	26%	3,023	11%	76,015	24%
Psychosocial disability	25,234	9%	2,630	10%	27,864	9%
Developmental Delay	12,901	5%	3,659	14%	16,560	5%
Other Neurological	13,246	5%	1,141	4%	14,387	5%
Cerebral Palsy	13,424	5%	548	2%	13,972	4%
Other Physical	12,171	4%	1,254	5%	13,425	4%
Hearing Impairment	10,901	4%	1,998	7%	12,899	4%
ABI	10,052	4%	613	2%	10,665	3%
Visual Impairment	6,989	2%	450	2%	7,439	2%
Multiple Sclerosis	5,955	2%	356	1%	6,311	2%
Global Developmental Delay	4,223	1%	1,138	4%	5,361	2%
Stroke	3,870	1%	402	2%	4,272	1%
Spinal Cord Injury	3,761	1%	238	1%	3,999	1%
Other Sensory/Speech	3,014	1%	136	1%	3,150	1%
Other	464	0%	40	0%	504	0%
Total	285,086	100%	26,688	100%	311,774	100%

Harm caused by unsafe and ineffective continence care

Incontinence can have harmful effects on physical and mental health and quality of life.

Incontinence is independently associated with poor quality of life for people with disability. It has been shown that, in adults, urinary incontinence as a consequence of multiple sclerosis¹⁵; stroke¹⁶; spinal cord injury¹⁷; and Parkinson's¹⁸ has a significant negative impact on quality of life.

Unsafe and ineffective continence care and incontinence management can increase the risk of detrimental health outcomes such as urinary tract infections in people with spinal cord injuries¹⁹ and those who have had strokes²⁰.

Safe and effective continence assessments are vital to the health and wellbeing of NDIS participants. Continence care plans are particularly important for participants to enable them to participate as fully as possible both socially and in the workforce. Optimising their continence, maximises their chance of achieving their personal goals.

Participation: social, education and labour force

Social participation is key to the wellbeing of NDIS participants and builds towards both educational participation and labour force participation²¹.

Incontinence affects people's ability to engage in social situations, education and employment. According to the *Survey of Disability, Aging and Carers 2009*²², Australians with severe incontinence are particularly limited in their ability to engage in social situations, education and employment.

Incontinence can impact on levels of social participation and quality of life. A consequence of this is that a person's ability, willingness or confidence to go out, or go out as often as they like, may be affected. Of people aged 15 or over living in households, and with severe incontinence, just over 50% reported that they could not go out as often as they would like¹⁴.

In 2009, there were 29,500 young people aged 5–20 years with severe incontinence and just over 90% were attending school. Of those attending school with severe incontinence: 40.5% were attending a mainstream school, 27.2% were attending a special school, and 23.6% were attending a special class in a mainstream school.

The labour force participation rate for people aged 15–64 who always or sometimes needed assistance with bladder or bowel control was 20.4%. This was substantially lower than those who had difficulty with bladder or bowel control but needed no assistance (42.3%) and those who had no difficulty at all (56.8%).

Participation in the labour force differs markedly for people with disability living in households depending on whether they needed assistance with managing bladder or bowel control or not. Only 20.4% of people who always or sometimes needed assistance with bladder or bowel control were participating in the labour force compared with 42.3% who needed no assistance, but had difficulty with bladder or bowel control. In contrast, labour force participation rate for people without disability (aged 15 to 64) was 83.2%¹⁴.

People with disability, who have incontinence, are less likely to be employed than both people without disability and those with disability without incontinence. The employment rate of people with disability who have severe incontinence is 0%, with moderate incontinence is 34% and slight incontinence is 36%²³.

Expert consultation group

As part of this process, the following organisations and people were consulted and provide the expertise and evidence base which underpin our collective concerns and recommendations:

- Contenance Foundation of Australia Victorian Branch Inc (registered NDIS service provider), Executive Officer: Therese Wesselink, Physiotherapist
- Contenance Foundation of Australia in NSW Inc. (registered NDIS service provider), Manager: Donna Heggie
- Contenance Nurses Society Australia CoNSA National President: Joanne Dean GradCert (Spinal cord injuries), GradDip (Gerontic nursing), MAdvNurs, Nurse Practitioner
- Contenance Nurses Society Australia CoNSA NSW Representative: Kylie Wicks MN (Research), BHlth, DipAppSc (Nursing)
- GV Health, Regional Continence Service (Greater Shepparton, Moira and Strathbogie):
 - Divisional Director, Primary Care, Julyan Howard
 - Clinical Coordinator, Regional Continence Service, Rochelle Chadwick, Nurse Continence Specialist
- Barwon Health Continence Service McKellar Centre, Monica Harrop, Continence Nurse Consultant
- Australian Rehabilitation Nurses Association Strategic Initiatives Sub-Committee - NDIS working group.

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Appendix 1. Prevalence of incontinence in some groups of people with disability

Condition	Population	Country	Urinary incontinence		Faecal incontinence	Reference
Spina bifida	Children 5 years and older	United States	30.1%		29.7%	Sawin KJ, Liu T, Ward E, Thibadeau J, Schechter MS, Soe MM, Walker W, NSBPR Coordinating Committee. The National Spina Bifida Patient Registry: profile of a large cohort of participants from the first 10 clinics. <i>The Journal of Pediatrics</i> . 2015 Feb 1;166(2):444-50.
Spina bifida	Young adults	Netherlands	60.9%		34.1%	Verhoef M, Lurvink M, Barf HA, Post MW, Van Asbeck FW, Gooskens RH, Prevo AJ. High prevalence of incontinence among young adults with spina bifida: description, prediction and problem perception. <i>Spinal Cord</i> . 2005 Jun;43(6):331.
Cerebral palsy	Children and adults	Systematic review	46%			Samijn B, Van Laecke E, Renson C, Hoebeke P, Plasschaert F, Vande Walle J, Van den Broeck C. Lower urinary tract symptoms and urodynamic findings in children and adults with cerebral palsy: A systematic review. <i>Neurourology and Urodynamics</i> . 2017 Mar;36(3):541-9.
Down syndrome	Children 4-12 years 4-51 years	Netherlands	64% 15.9%		14.2%	Niemczyk J, Schäfer S, Becker N, Equit M, von Gontard A. Psychometric properties of the "parental questionnaire: Enuresis/urinary incontinence"(PQ-EnU). <i>Neurourology and Urodynamics</i> . 2018 Sep;37(7):2209-19.
Autism	5-16 years	Germany	NE 30%	DUI 25%	12.5%	von Gontard AV, Pirrung M, Niemczyk J, Equit M. Incontinence in children with autism spectrum disorder. <i>Journal of Pediatric Urology</i> . 2015 Oct 1;11(5):264-e1.
Multiple sclerosis	Adults	Australia	50%		14%	Khan F, Pallant JF, Shea TL, Whishaw M. Multiple sclerosis: prevalence and factors impacting bladder and bowel function in an Australian community cohort. <i>Disability and Rehabilitation</i> . 2009 Jan 1;31(19):1567-76
Stroke	Acute stage 12 months	Germany	51% 32%			Kolominsky-Rabas PL, Hilz MJ, Neundoerfer B, Heuschmann PU. Impact of urinary incontinence after stroke: results from a prospective

					population-based stroke register. Neurourology and Urodynamics. 2003;22(4):322-7.
Spinal injury	Within 1 year of injury 20 years after injury	United Kingdom	82.3% 85.9%	78.5% 83.3	Savic G, Frankel HL, Jamous MA, Soni BM, Charlifue S. Long-term bladder and bowel management after spinal cord injury: a 20-year longitudinal study. Spinal cord. 2018 Jun;56(6):575.