Submission to the *NDIS Annual Pricing Review 2021-22* consultation

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Background

The Continence Foundation of Australia welcomes the opportunity to make a submission to the National Disability Insurance Agency's (NDIA) consultation on the *Annual Pricing Review 2021-22*.

The Continence Foundation of Australia (the Foundation) is the peak body for promoting continence (bladder and bowel control) health. The expertise of the Foundation in education, awareness, information, advocacy and NDIS service provision alongside representation in each state and territory means that we are best placed to represent the interests of individuals, carers and health professionals in relation to continence and disability.

The Foundation is deeply concerned that the changes that we consider essential and advocated for in our previous submission to the *Annual Pricing Review 2020-21* consultation have not been implemented nor has any satisfactory action been taken to address the issues raised in our submissions in the last two years. Our request that Nurse Continence Specialist (NCS) be remunerated equitably with allied health professionals has not been put into place. This is both inequitable treatment of skilled health workforce roles and it also exacerbates the inequitable provision of and access to specialist continence services in rural and remote regions. Together these contribute to low provision of continence health care for vulnerable population groups particularly in rural and remote communities.

Incontinence currently affects one in four Australian adults[1] and is recognised as a disability under the Disability Discrimination Act 1992. Incontinence is an even more common experience for people with disability with one in three experiencing incontinence.[2.] For specific disabilities, the incidence of incontinence is higher and can present significant challenges:

- Up to 57% of people with autism experience incontinence.[3]

- 56% of people with cerebral palsy experience incontinence.[4]
- A systematic review has found experience of incontinence to be significantly associated with challenging (aggressive) behaviour in adults with intellectual disability.[5]

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 sclerosis[6], stroke[7], spinal cord injury[8], and Parkinson's[9] has a significant negative impact on quality of life.

Given that incontinence is commonly associated with these disabilities, people with these disabilities should be provided with a comprehensive continence assessment as part of care planning and appropriate therapy and ongoing support should be available within NDIS plans with pricing provisions sufficient to ensure availability of adequate specialist continence health care and support.

The NDIA must not only be cognisant of these concerns to enable and empower people with disability, including incontinence, but should also act as a steward to facilitate access to contemporary, evidence-based and effective continence care.

Recommendations

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

Recommendation 1

The fee for service for an expert nurse including a Continence Nurse Specialist 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, rural and remote areas by:

- increasing the fee for service for an expert nurse including a Continence Nurse Specialist working at the level of a Clinical Nurse Consultant, providing a continence assessment, to be the same as the fee for service for an allied health professional (episodic therapy rate) in remote and very remote areas.
- increasing the amount of travel costs that can be claimed for delivering services to participants who live outside of metropolitan centres through in kind contributions.

Evidence for Recommendation 1

NCS qualifications and expertise

Health specialists within the NDIS provide an essential service that must be remunerated commensurate to their experience and qualifications to enable high quality and sustainable service provision. However, the role of NCSs and their specialised skill set in the NDIS continues to be disregarded as a highly trained specialist health role and practice and the fees for service that these professionals can claim are significantly lower than their expertise justifies.

An NCS is a Registered Nurse (who may also be a Midwife) with relevant post-graduate qualifications and/or skills and expertise in continence care who provides services that are an integral part of an interdisciplinary approach to care of people with bladder, bowel and pelvic floor muscle dysfunction.[10,11] This definition is supported by the Continence Nurses Society Australia's Practice Standards which help define and guide the practice of the NCS throughout Australia and describe continence nursing practice in parallel with Registered Nurse Standards for Practice.[10,12]

NCSs 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 alongside education and support of people with disability require NCSs to be highly skilled. Additionally, they must keep informed about the latest trends in treatment and available products to enable person-centred care based on the best available evidence.

The role of the NDIA as a market steward

The NDIA's role as an effective market steward is not yet effective for equitable access to disability care services for incontinence. The NDIA has yet to recognise incontinence as a disability, its high incidence with other disabilities and as a health care issue associated with a wide range of disabilities. Compared to allied health professional services such as occupational therapy, which tend to receive a higher level of funding for assessment and ongoing therapy sessions in NDIS plans, the funding for individual continence needs often focuses on continence products and one-off continence assessments with lower pay rates than allied health counterparts. This considerably limits the capacity of continence services to ensure therapeutic care is provided that is responsive to individual needs and that improves the quality of life, health and social participation of individuals. This also threatens the viability of these services in disability care in the long-term due to lack of funding in NDIS plans for this.

Insufficient pay rates for Nurse Continence Specialists

The Foundation is disappointed that its submission to the *NDIS Annual Pricing Review 2020-2021* advocating for pay parity between NCSs and allied health professionals has not been implemented. The NDIA's pricing arrangements for specialist continence services do not align with roles based on their qualifications and experience leading to, and perpetuating, undersupplied or thin markets which are inefficient. The continued undervaluing of NCSs has meant that the cost-benefit ratio of providing such services under the NDIS often ends with a negative result. For the last two years, NCSs have generally only been able to claim through a lower paying cost item *Delivery of health supports by a Clinical Nurse Consultant – Weekday Daytime* for their services equating to $146.72 per hour, however allied health professionals have been able to claim $193.99 for equivalent services.[13] This is despite there being no requirement for allied health professionals to have specialist experience nor specialist expertise or training. **The fees for their services are higher despite the training and qualification requirement for these roles being lower than those for a nurse providing specialist continence services** and working at the level of a Clinical Nurse Consultant.

When placed in the context of overall funding in a NDIS plan, lower pay rates for NCSs lead to increasing pressure on service sustainability and quality of care delivered. NDIS plans often only fund a minimalistic level of care for participants experiencing incontinence leading to a much higher work-cost ratio for NCSs compared to allied health services. This is because the NDIS may only fund an initial continence assessment but not ongoing therapy for continence care unlike allied health services. This results in a number of hidden costs that continence services are burdened with but that are supported for allied health services due to both the higher level of pay and ongoing funding for therapy sessions. For the cost of a single continence assessment that is conducted once a year, continence services have to ensure a year's worth of administrative costs including participant onboarding, assessment, reporting, management and coordination are covered.

The difference in cost to service provision becomes stark when putting this into practise. Assuming that an adequate health assessment can be conducted in four hours each by a NCS, when compared

to an allied health professional in their respective fields, continence services must provide a year's worth of administration costs as outlined on top of a comprehensive assessment for $586.88 (at $146.72 per hour) but an allied health therapy service only has to cover the assessment for $775.96 (193.99 per hour). Allied health professionals are more likely to receive funding for ongoing support at an average of ten standard therapy hours per year which means a further $1939.90 is available, and can also be utilised to help cover a year's worth of administration costs for client management. This means that continence services addressing NDIS participant continence needs are left without even a minimal level of funding needed to provide even more specialised services than allied health services resulting in a significant risk of specialist continence services withdrawing from the market.

Not only does this create considerable access issues for NDIS participants with continence needs, it compromises quality of assessment and greater risk of negative health outcomes. Continence-related care that is not contemporary, evidence-based and effective can increase the risk of detrimental health outcomes such as urinary tract infections in people with spinal cord injuries[14] and those who have had strokes.[15] Further, the Foundation has recent information that two private services which do not have staff trained adequately in continence care provided substandard assessments and reports for participants which led to the participants requiring reassessment by another service. This means cost to participants doubled and consequently resulted in complaints of poor service. Further, these services sought help from the National Continence Helpline, an Australia-wide advice and support service staffed by NCSs. This evidence highlights the substantial gap between the care and service provision being enabled by existing frameworks compared to the qualified and proficient specialist continence services that should be supported.

Aligning NDIS and comparable government scheme pricing arrangements

NDIA pricing arrangements are not appropriately aligned with comparable national and state level government schemes for nursing and therapy supports. The NDIA should take note of these schemes as they affirm pay rates that more closely reflect NCS qualifications and expertise. For example, the Commonwealth Home Support Program sustains pay rates of $104-129 per hour for nurses and $95-$125 for allied health and therapy services.[16] In Victoria, current award rates for the equivalent of NCSs and Allied Health Therapists are $2060 and $2113.80 per week respectively.[17,18] With respect to the nature of the market, the NDIS has, we assume unintentionally, misaligned the value of NCSs commensurate to their qualifications and experience when compared to government funded services at state and national levels. As a market steward, raising NCS pay rates so they reach parity with allied health services will not only support high quality continence services entering the market but maintain existing services in an undersupplied or thin market.

The NDIA has a responsibility to maintain and expand the supply of high-quality disability supports, including qualified NCSs as a market steward. To ensure this supply of qualified NCS the NDIA must work to enable a more sustainable business model to reduce the risk of qualified continence service providers exiting the market. UK studies have found that there is approximately one NCS per 2,500 people with faecal incontinence and one per 8400 people with urinary incontinence[19,20] with Australia likely to have similarly high ratios. Even with this low overall ratio, it is likely that NDIS facilitated obstructions related to pay, administrative costs and limited funding allocated for comprehensive continence assessments will prove too great an impediment for many existing continence services to join, let alone stay to provide contemporary, evidence-based and effective continence care further marginalising access to much needed care. The NDIA must benchmark itself with comparable government scheme pricing arrangements to better reflect NCS expertise and qualifications to maintain a more equitable level of specialist continence service provision and enable high quality care.

Access to comprehensive continence assessments by qualified practitioners

High quality health service provision begins with a comprehensive assessment conducted to understand all relevant aspects of individual health. Qualified health practitioners, such as NCSs, have to demonstrate advanced health assessment skills within the NCS scope of practice - history taking, bladder and bowel diary and physical examination, work in partnership with NDIS participants to determine priorities for action or referral and conduct assessments which are holistic and culturally appropriate.[10]

The requirements for an NCS 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. An NCS uses a whole-systems assessment process in the same way as an Occupational Therapist assesses functional capacity and needs. Comprehensive continence assessments and management plan reports conducted by NCSs are necessary and provide multiple health, economic and quality of life benefits.

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 improve their quality of life.[21] During the study, a continence management plan was developed 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 $3617.15 per person per year.
- Improved participant independence in activities of daily living, three months after implementation.[21]

This evidence led to the recommendation that service providers '*should ensure a comprehensive continence assessment is completed by a qualified continence specialist*'.[21] The NDIA must recognise the value of continence assessments conducted, and management plans developed, by qualified NCSs and ensure they are paid at an equivalent rate to allied health counterparts to reduce long-term costs of funding ineffective continence products, increase independence and independent toileting in NDIS participants.

Sudden major changes to continence-related policy by the NDIA can exacerbate the need to access comprehensive continence assessments. This is especially the case for NDIS participants who have little information about appropriate pathways to NCSs who can assess, diagnose and provide support plans for participants. Following a major policy change to include some disability-related continence supports in the NDIS in 2019, it is estimated 40-60,000 participants required reassessment in light of the change. Considering that only 2% of 1672 NDIS participants surveyed in an Australia-wide study had funded healthcare support for continence nursing[22], it is highly unlikely that even one-tenth of the affected participants had appropriate access to NCSs for comprehensive continence assessments. To address this, education and appropriate care pathways should be set up to increase NDIS participant knowledge of effective care options and access to care. Otherwise, the

chasm between existing NDIA facilitated services and participant need is unlikely to be addressed in full for years to come.

The Foundation contends that greater access to both specialist comprehensive continence health assessments and capacity building supports are necessary to deliver improved outcomes. The NDIA should actively recognise the need for continence services that can deliver contemporary, evidence-based and effective continence assessments rather than lower quality alternatives and ensure the stewardship of the market to provide equitable access to these services. Further, the addition of a rural and remote loading would maintain and increase supply through increased pay rates and facilitate greater outreach, quality of service and therapeutic and social supports for participants with continence needs.

Evidence to support Recommendation 2

Addressing inequity of access in rural, regional and remote areas to continence assessments, management plans and related supports provided by qualified health professionals should be a mainstay of NDIA policy. Existing mechanisms within the NDIS Price Guide already support, to some extent, service provision for non-metropolitan NDIS participants through a higher fee for service in these areas. Whilst this supports the costs for additional travel and the lack of service availability it does not account for the disparity between Clinical Nurse Consultant and allied health professional pay rates despite them facing the same costs. This change is especially important to implement for specialist service delivery which are less common than general services in non-metropolitan areas and should be offered to NCSs as part of the overall rise in pay rates to become equitable with allied health therapist funding.

This increase in pay is of particular importance to remote communities that require in-person consultations due to existing cultural barriers and health needs that telehealth services will not overcome. This includes remote indigenous communities for whom studies have shown between 23 and 54% of Aboriginal and Torres Strait Islander people living in remote communities experience incontinence.[23,24] Incontinence within indigenous communities is significantly associated with dementia, stroke, head injury, falls, depressive symptoms, epilepsy and poor mobility.[24-26] In order to build a connection with and be able to deliver culturally safe continence services to Aboriginal and Torres Strait Islander communities, having direct in-person access is vital as it can facilitate necessary therapeutic supports such as examination of underlying problems through intrusive assessments which can greatly assist with improved quality of life.

Adequately supporting remote communities, therefore, requires higher fees for service in non-metropolitan areas in line with existing allied health professional rates. In addition, the amount of travel that can be claimed to facilitate specialist continence is limited to one hour for a round trip this must also be increased through in-kind contributions as existing fee structures will not nearly compensate services for some regional and almost all remote area travel. Together, these changes will help to promote and deliver equitable, person-centred and culturally appropriate continence care for NDIS participants across Australia.

In light of the above evidence, the Foundation reiterates its recommendations to the *NDIS Annual Pricing Review 2021-22* consultation:

Recommendation 1

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Recommendation 2

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