Submission to the Current Scheme Implementation and Forecasting for the National Disability Insurance Scheme consultation

February 2022

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Summary

The Continence Foundation of Australia welcomes the opportunity to respond to the *Current Scheme Implementation and Forecasting for the National Disability Insurance Scheme (NDIS)* review conducted by the Joint Standing Committee on the National Disability Insurance Scheme.

The Foundation supports the view that any review of the NDIS and any approach to transform it must place the people it supports at its centre.[1] The NDIA must act in conjunction with Australian laws to give effect to our obligations under the Convention on the Rights of Persons with Disabilities (the Convention).[2] The Convention recognises the need to provide health services needed by people living with disabilities and their right to the enjoyment of the highest attainable standard of health without discrimination[3] and the NDIS must be shaped to adhere to this aim.

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.

In Australia, one in four adults experience incontinence[4] and it is recognised as a disability under the Disability Discrimination Act 1992. For people living with a disability, it is an even more common experience with one in three experiencing incontinence[5] which is likely to be further exacerbated for NDIS participants due to the higher impact and permanence of the disability they are likely to experience. The experience of incontinence is significantly associated with several key impacts on individuals. It is independently associated with lower quality of life for people living with disability[6-9] and it can also result in lower socioeconomic and physical activity.[10,11]

Nevertheless, incontinence remains largely unrecognised as a key co-morbidity with other disabilities and as a disability in its own right by the National Disability Insurance Agency (NDIA). This has led to a series of discrete issues that affect NDIS participants in gaining access to and receiving appropriate assessment and care from experienced and qualified continence specialists, support to maintain independence and facilitate community participation with regard to continence. This brings

into question the performance of the NDIA as a steward and facilitator for NDIS participants experiencing incontinence or need support with their continence care to become empowered, independent and better able to manage their condition.

In consideration of these issues, the Foundation makes the following recommendations to the Joint Standing Committee on the NDIS:

1. **Incontinence be recognised as a disability under the NDIS, as per the Disability Discrimination Act 1992, and a key co-morbidity for NDIS participants with other disabilities.**
2. **The adoption of independent, evidence-based tools, guides and resources to optimise continence assessment and care and facilitation of continence related products and services in the NDIS.**
3. **Informational and referral pathways for continence assessment and care in the NDIS to be developed in consultation with relevant stakeholders.**
4. **The fee for service for an expert nurse including a Nurse Continence 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) as reflected in the health sector.**
5. **Improve accessibility to continence services by NDIS participants in non-metropolitan, rural and remote areas by:**
    a. **increasing the fee for service for an expert nurse including a Nurse Continence 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.**
    b. **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 particularly where access to specialised services is lacking.**
6. **Ensure adequate funding for continence-related issues, based on need, when a prospective NDIS participant is transitioning into the NDIS.**
7. **Link funding for specialist continence assessments where continence products are part of an NDIS plan.**
8. **Link continence product use with capacity building supports to promote, establish, and maintain continence.**

The Foundation will be responding to the terms of reference a-c as part of this submission:

a. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:
    i. the availability of support outside the NDIS for people with disability (e.g. community-based or ‘Tier 2’ supports), and
    ii. the future of the Information, Linkages and Capacity Building grants program;
b. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;
c. The reasons for variations in plan funding between NDIS participants with similar needs, including:
    i. the drivers of inequity between NDIS participants living in different parts of Australia,
    ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and
    iii. measures that could address any inequitable variation in plan funding;

Support for incontinence is marginalised in the NDIS

Incontinence in the NDIS is often sidelined as an issue despite being of significant value, weight and concern for many people living with a disability. Incontinence is a highly prevalent but hidden condition that one in four Australian adults experience.[4] For people living with a disability, it is an even more common experience with one in three experiencing incontinence.[5] For NDIS participants, who usually have a greater level of functional impairment, this will likely mean a higher proportion require safe and effective continence supports. Incontinence has a significant burden on Australians across the life course and must not be diminished in importance given the overall impact:

- Occurrence of incontinence is not inevitable with age. Over half of women and more than one in three men living in the community with incontinence are under 50 years of age.[4]
- The burden of disease of incontinence is associated with almost 140,108 Disability Adjusted Life Years (DALYs) or years of life lived with disability annually.[4]
- People aged 15 and over with severe incontinence are more likely to report being in fair (34%) or poor (22.2%) general health than people without severe incontinence (24.8% and 10.4% respectively).[12]
- Incontinence is a common co-morbidity with other disabilities including autism[13], down syndrome[14], stroke[15], multiple sclerosis[16], cerebral palsy[17] and spina bifida.[18]
- 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.
- It is also a key risk factor for other chronic conditions[19] including cancer, diabetes, asthma, heart/cardiovascular disease[20] and constipation.[21]

1. **The Foundation advocates for incontinence be recognised as a disability under the NDIS and a key co-morbidity for NDIS participants with other disabilities.**

Despite its prevalence and impact, there is little support within the health and disability sectors in Australia, including the NDIS, for a number of reasons. These involve multiple issues including stigma, lack of awareness, knowledge by both consumers and health professionals and access to or information about appropriate continence services. Combined, these create a situation in which minimal actions are taken at an individual and systematic level to address key concerns about continence management and treatment.

Raising the issue of incontinence can be a challenge for consumers and professionals alike. Incontinence can be stigmatising, affect mental health and quality of life and lead to withdrawal from social contact, physical activity and work.[10,11] Several Australian studies have found that 70% of individuals do not seek help from health professionals for urinary incontinence[22,23] and this is even more likely for faecal incontinence. With health professionals including doctors not proactively raising the topic of incontinence with consumers, it is difficult for treatment and management to occur. The Foundation's Nationally Representative Consumer Survey (National Survey) indicates that 84% of the time, the topic of incontinence is raised with a doctor by the consumer themselves.[20] This precludes the potential benefit of pro-active treatment for incontinence and reduces the role of the NDIS in ensuring that clients with incontinence have and are encouraged to have primary and specialist health care with this condition. A lack of communication about incontinence also means there is no visible pathway to specialist continence treatment and support. This suggests the need for greater efforts to be made to educate and train health professionals including people employed by the NDIS in continence-related issues to engage sensitively with NDIS participants.

The lack of contact and action to address incontinence is likely already entrenched in the NDIS. The disability workforce, like the general health workforce, are unlikely to be adequately trained in continence-related care. While existing qualifications such as the Certificate IV in Disability Support qualification have incorporated more continence-related care content as part of a recent 2021 review[24], these are still considered inadequate to ensure evidence-based, contemporary or effective continence care by newly employed Disability Support Workers, Support Coordinators or NDIS Planners. It is noted however that completing the Cert IV is still better than the situation for other NDIS employees who would have completed the less adequate qualification in the past or who do not have a qualification at all. A University of New South Wales survey found that only 31 per cent of workers strongly agreed that their skills were well matched to the work they are asked to do.[25] In addition, recent data from the Continence Foundation of Australia's National Surveys shows a significant increase in the number of people with disability reporting incontinence (23% to 31%) between 2017 and 2020.[20,26] Combined, this is a significant reason for concern as many more NDIS participants will be dependent on NDIS workers to provide assistance, guidance and support to empower and facilitate their independence but which they have not been prepared for.

It is important that independent tools, guides and resources which are evidence-based and effective are utilised to address the existing gaps in continence care and facilitation of products and services in the NDIS. The Foundation has developed evidence-based, contemporary tools, guides and resources to support direct care and support operations for these NDIS roles. The Foundation provides several avenues for disability care support including *Continence Support Now* and *Aspects of Continence*. The *Continence Support Now* application is an online pocket guide for disability and aged care workers providing bladder and bowel support in real time. *Aspects of Continence* is an online course which shows learners how to apply knowledge to practice and is aimed at disability support workers and nurses. The Foundation is also willing to work with the NDIA to develop material to guide NDIS Planners and Support Coordinators on facilitating appropriate continence-related care, referrals and information pathways to better enable high quality health outcomes for NDIS participants. Together, these can form a sound basis for change at a granular level to facilitate better health outcomes.

There is also a need for the Support Coordinators and NDIS Planners to understand management of incontinence or bladder and bowel health is time consuming and expensive. An application should not be rejected because the person's disability is solely continence related. There should not be an expectation that other state and national funding schemes should wear the costs of these continence aids because the person is deemed not to be disabled enough. These other scheme are not able to adequately covered the equipment needs, for example, of people with a spinal cord injury who require intermittent catheterisation 4-6 times a day plus bowel care involving transanal irrigation or enemas and continence products.

2. **The Foundation recommends the adoption of independent, evidence-based tools, guides and resources to optimise continence care and facilitation of products and services in the NDIS.**

Incontinence has no clearly defined barriers or pathways within the NDIS

A clear distinction between responsibilities for continence-related issues between the NDIA and the health sector has not been drawn by either side. Eligibility to claim disability-related health supports is limited to ongoing needs, directly related to a significant and permanent functional impairment and must not be the usual responsibility of the health system. This can lead to potential harm, health complications and unnecessary delay in receiving appropriate care. For example, anecdotal evidence from NDIS registered continence clinics suggests that this can lead to participants being shifted from the health to the disability sector and back again for support. The Foundation has also received informal advice that this can affect access to certain continence products such as wet wipes and gloves which can lead to frustration and poorer health outcomes. To address this, the NDIS should clearly outline responsibilities for the NDIA for continence-related issues to be complemented with the health and other sectors. Efforts to resolve these issues should include recurrent program funding for system navigators[27], assisting people with disability, their carers and supporters to successfully address their needs across the NDIS, disability, health and other sectors. This would provide informational and referral pathways for continence care that lead to effective, contemporary and evidence-based care.

To gain access to funding and support for continence related issues, NDIS participants living with incontinence or continence related issues need to have knowledge of, and gain access to, appropriate continence services. Without access to a qualified and/or experienced health professional such as a Nurse Continence Specialist or Pelvic Floor Physiotherapist to assess their needs, the participant is resigned to being dependent on their NDIS planner's expertise which is likely to be minimal as outlined previously. Otherwise, it can lead to minimal if any continence support from the NDIS. For NDIS participants with incontinence or continence related issues, there is no common visible pathway to specialist continence treatment and support and this must be addressed in the form of guidance to help shape continence management and treatment responses. The Foundation's National Continence Helpline (NCHL), a free national telephone information, advice and support service staffed by Nurse Continence Specialists (NCS) who also provide resources and information on access to local continence services, can act as one such pathway to address these concerns.

Learning and early life childhood interventions also required continence-specific referral pathways

The Early Childhood Early Intervention approach to support children younger than seven years of age should also be reviewed as incontinence has a direct impact on children's participation in schooling activities. 19% of children starting primary school are estimated to have incontinence.[28] Many children with some form of incontinence at this age continue to have incontinence into adolescence and adulthood.[29,30] Incontinence can impact participation and engagement in formal learning settings. Children with incontinence are more likely to experience bullying and to have higher absenteeism.[31-34] Anecdotally, parents report their children with incontinence are more likely to miss out on educational opportunities such as excursions and school camps. The Foundation has received additional feedback from continence specialists that the COVID-19 pandemic has affected toilet training for children who are NDIS participants, and the level of stress for their carers, due to a reduction in supports at the school and in respite. In this case, as above, appropriate referral pathways are required to optimise health and quality of life outcomes for both the children and their carers.

3. **The Foundation advocates for informational and referral pathways for continence care in the NDIS to be developed in consultation with relevant stakeholders.**

Incontinence is not appropriately planned for in the NDIS resulting in inadequate service support

Continence support is not recognised for its value to participants living with incontinence. The lack of support for continence services, and for NDIS participants experiencing incontinence and their carers, leads to multiple barriers to care, the reduction of available care and establishes continence-related needs as lower priority for the different actors involved.

Workforce development

The NDIA has a responsibility to maintain and expand the supply of high-quality disability supports, including qualified NCSs as a market steward. The NDIA's pricing arrangements for specialist continence services do not align with roles based on their qualifications and experience leading to, and continuing, undersupplied or thin markets which are inefficient. 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.[35,36] This places NCS roles over and above allied health therapeutic roles in terms of being a highly trained specialist health role but this is not reflected in higher pay rates, let alone pay parity, under the NDIS. Compared to allied health professional services such as occupational therapy, which tend to receive a higher level of funding for assessment ($193.99/hr) 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 (146.72/hr).[37] This stands in unambiguous contrast with other comparable national and state level government schemes for nursing and therapy supports. 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.[38] In Victoria, current award rates for the equivalent of NCSs and Allied Health Therapists are $2060 and $2113.80 per week respectively.[39,340]

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 workcost 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. There is a stark contrast between what NCSs are able to achieve with their allocated fund hours compared to what allied health therapists can do. Assuming that an adequate health assessment can be conducted in four hours, continence services must provide a year's worth of administration costs as outlined above, on top of a comprehensive assessment for the funded amount of $586.88 (4 hours at $146.72 per hour) but an allied health therapy service has just the assessment costs to cover with the funding they receive (i.e. $775.96 or 4 hours at $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 to cover a year's worth of administration costs for client management.

Information provided by the Foundation's members operating continence clinics points to the need to incorporate costs associated with individual needs such as interpreter services. This requires even more hours than usual to ensure a comprehensive assessment is understood and conducted. This means that continence services working with NDIS participants are not receiving the minimal level of funding needed to provide the more specialised services when compared to allied health services. This means that there is a significant risk of specialist continence services withdrawing from the market.

4. **The Foundation advocates for 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).**

Inequity for rural and remote areas

Addressing inequity of access in rural, regional and remote areas to continence assessments, therapy and related supports by qualified health professionals should be a key part of NDIS policy. Despite existing mechanisms implemented within the Price Guide which already support higher costs in these areas, they do not account for the gap between NCS and allied health professional pay rates. 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.

5. **The Foundation advocates for improving accessibility to continence services by NDIS participants in non-metropolitan, rural and remote areas by:**
    a. **increasing the fee for service for an expert nurse including a Nurse Continence 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.**
    b. **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.**

The necessity of contemporary, evidence-based and effective continence care in the NDIS

During the COVID-19 pandemic, it has become apparent that continence care is very much a necessity, but services remain scarce. An Australia-wide survey found only 2% of 1672 NDIS participants had funded healthcare support for continence nursing.[41] This is far less than the one in three people with disability who experience incontinence[5] highlighting the immense gap to be closed for NDIS participants who live with incontinence.

The same survey found that since the start of the pandemic, continence care is valued as essential. While 40% of NDIS participants receiving occupational therapy and 45% receiving physiotherapy reduced the number of consultations they attended, only 19% of participants who attended continence nursing consultations attended fewer sessions. More participants who received continence care felt that remote delivery was effective compared to other consultations like psychology (71% vs 57%). This is a testament to the high quality and effective work done by NCSs.[41] Despite this, scarcity of NCSs and NDIS support for NCSs is a key concern.

Overall, major workforce issues identified by NCSs[42] include:

- job losses or cuts to positions,
- NDIS actually or potentially causing job losses,
- Downgrading of positions from NCS roles to generalist Registered Nurse roles but still reliant on continence skills,
- Workplace reviews or restructures that lead to loss of or downgrading of positions, and
- Use of nursing staff without continence qualifications or other disciplines that were previously CNS roles.

These factors and other continence-related changes by the NDIA also have practical implications for access and support. 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% participants had funded healthcare support for continence nursing[41], it is highly unlikely that even one-tenth of the affected participants had appropriate access to NCSs for comprehensive continence assessments.

Concerns about substandard continence care

The Foundation has significant concerns that substandard continence care is being facilitated by the NDIS and that this results in considerable consequences for NDIS participants. The Foundation received recent information from the NCHL that two private services, which did not have staff trained adequately in continence care, provided substandard assessments and reports for participants, resulting in the need for reassessment by another service. This meant double the cost to participants and complaints about the poor service. This is not uncommon with several instances of consumer complaints about 'continence' nurses who had little to no knowledge about incontinence and appropriate management practices.

It is also a noteworthy concern that the Foundation has received advice that multiple private organisations with unqualified nursing staff who conduct continence assessments and management have asked if their nurses can 'shadow' a continence clinic's own qualified staff to observe assessments and enable them to work privately. 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.

The impact on NDIS Participants and carers

The impact of a lack of adequate support is also keenly felt by current and prospective NDIS participants. For prospective NDIS participants, a lack of appropriate budget for incontinence products during the transition period into the NDIS can stretch into months for some participants which means their interim needs are not supported. This can lead to an inability to maintain their quality of life and reduces their participation in community and employment.

There is also anecdotal evidence that service providers in Victoria are finding it difficult to find suitably qualified NCSs. A lack of NCSs combined with an increased demand from NDIS participants impacts on existing private and public services for the general population and NDIS participants with a two- to three-month waitlists being common.

Further evidence shows that the COVID-19 pandemic has reduced access to continence care. The reduction in face-to-face management has led to heightened carer stress according to a Foundation member who runs an NDIS registered continence clinic, and feedback from an NCS and parent of a NDIS recipient has also indicated there is a need for ongoing therapy hours to be funded alongside assessment. This would be in line with other therapeutic or allied health supports who normally receive funding for advice, planning, follow up, parent education and report writing which would pre-empt high quality care services and ease the burden of care on all parties involved.

6. **The Foundation advocates for adequate funding for continence-related issues when a prospective NDIS participant is transitioning into the NDIS based on need.**
7. **Link funding for specialist continence assessments where continence products are part of an NDIS plan.**
8. **Link continence product use with capacity building supports to promote, establish, and maintain continence.**

Conclusion

In consideration of these issues, the Foundation makes the following recommendations to the Joint Standing Committee on the NDIS:

- Incontinence be recognised as a disability under the NDIS and a key co-morbidity for NDIS participants with other disabilities.
- The adoption of independent, evidence-based tools, guides and resources to optimise continence care and facilitation of products and services in the NDIS.
- Informational and referral pathways for continence care in the NDIS to be developed in consultation with relevant stakeholders.
- The fee for service for an expert nurse including a Nurse Continence 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).
- 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 Nurse Continence 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.
- Ensure adequate funding for continence-related issues when a prospective NDIS participant is transitioning into the NDIS based on need.
- Link funding for specialist continence assessments where continence products are part of an NDIS plan
- Link continence product use with capacity building supports to promote, establish, and maintain continence.

We look forward to working with the NDIA to support the changes necessary to ensure NDIS participants receive the continence care and support they need.

References

1. Bonyhady B. An analysis of the NDIA's proposed approach to Independent Assessments: a response to the National Disability Insurance Agency (NDIA) Consultation. Melbourne Disability Institute. 2021.
2. Australian Government. National Disability Insurance Scheme Act 2013. 2016. Available from: National Disability Insurance Scheme Act 2013 (legislation.gov.au) [Accessed 2022 February 21]
3. United Nations Human Rights Office of the High Commissioner. Convention on the Rights of Persons with Disabilities. 2007. Available from: OHCHR | Convention on the Rights of Persons with Disabilities [Accessed 2022 February 21]
4. Deloitte Access Economics. The economic impact of incontinence in Australia. The Continence Foundation of Australia: 2011
5. Continence Foundation of Australia (CFA). Nationally Representative Consumer Survey 2021. Continence Foundation of Australia Internal report. Unpublished
6. Zecca C, Riccitelli GC, Disanto G, Singh A, Digesu GA, Panicari L, Puccini F, Mattioli M, Tubaro A, Gobbi C. Urinary incontinence in multiple sclerosis: prevalence, severity and impact on patients' quality of life. European journal of neurology. 2016;23(7):1228-34.
7. Edwards DF, Hahn M, Dromerick A. Post stroke urinary loss, incontinence and life satisfaction: When does post-stroke urinary loss become incontinence? Neurourology and Urodynamics: Official Journal of the International Continence Society. 2006;25(1):39-45.
8. Liu CW, Attar KH, Gall A, Shah J, Craggs M. The relationship between bladder management and health-related quality of life in patients with spinal cord injury in the UK. Spinal Cord. 2010;48(4):319.
9. Pohar SL, Jones CA. The burden of Parkinson disease (PD) and concomitant comorbidities. Archives of Gerontology and Geriatrics. 2009;49(2):317-21.
10. Garcia JA, Crocker J, Wyman JF. Breaking the cycle of stigmatization: managing the stigma of incontinence in social interactions. Journal of Wound Ostomy & Continence Nursing. 2005 Jan 1;32(1):38-52.
11. Avery JC, Stocks NP, Duggan P, Braunack-Mayer AJ, Taylor AW, Goldney RD, MacLennan AH. Identifying the quality of life effects of urinary incontinence with depression in an Australian population. BMC urology. 2013;13(1)
12. Australian Institute of Health and Welfare 2013. Incontinence in Australia. Cat. no. DIS 61. Canberra: AIHW.
13. Niemczyk J, Wagner C, Von Gontard A. Incontinence in autism spectrum disorder: a systematic review. European Child & Adolescent Psychiatry. 2018;27(12):1523-37.
14. Niemczyk J, von Gontard A, Equit M, Medoff D, Wagner C, Curfs L. Incontinence in persons with Down Syndrome. Neurourology and Urodynamics. 2017 Aug;36(6):1550-6.
15. 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: Official Journal of the International Continence Society. 2003;22(4):322-7.
16. Khan F, Pallant JF, Shea TL, Whishaw M. Multiple sclerosis: prevalence and factors impacting bladder and bowel function in an Australian community cohort. Disability and rehabilitation. 2009 Jan 1;31(19):1567-76.
17. 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. Neurourology and Urodynamics. 2017 Mar;36(3):541-9.
18. 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. Spinal Cord. 2005 Jun;43(6):331.
19. Jacob L, López-Sánchez GF, Oh H, Shin JI, Grabovac I, Soysal P, Ilie PC, Veronese N, Koyanagi A, Smith L. Association of multimorbidity with higher levels of urinary incontinence: a cross-sectional study of 23089 individuals aged ≥15 years residing in Spain. British Journal of General Practice. 2021; 71(702): e71-e77.
20. Continence Foundation of Australia (CFA). Nationally Representative Consumer Survey 2020. Continence Foundation of Australia Internal report. Unpublished.
21. Vollebregt PF, Wiklendt L, Dinning PG, Knowles CH, Scott SM. Coexistent faecal incontinence and constipation: a cross-sectional study of 4027 adults undergoing specialist assessment. EClinicalMedicine. 2020;27:100572.
22. Avery JC, Gill TK, Taylor AW, Stocks NP. Urinary incontinence: severity, perceptions and population prevalence in Australian women. Australian and New Zealand Continence Journal. 2014;20(1):7-13.
23. Millard R. The prevalence of urinary incontinence in Australia. Aust. Continence Journal. 1998;4:92-99
24. SkillsIQ. Individual Support, Ageing and Disability – Draft 2. 2021. Available from: Individual Support, Ageing and Disability - Draft 2 - SkillsIQ :: Skills Service Organisation [Accessed 2022 February 22]
25. Cortis N, & van Toorn G. Working in new disability markets: A survey of Australia's disability workforce. UNSW Sydney. Social Policy Research Centre, 2020.
26. Continence Foundation of Australia (CFA). Nationally Representative Consumer Survey 2017. Continence Foundation of Australia Internal report. Unpublished
27. Department of Health. Aged Care System Navigator Measure. Available from: https://www.health.gov.au/initiatives-and-programs/aged-care-system-navigator-measure [Accessed 2020 October 20]

28. Sureshkumar P, Craig JC, Roy LP, Knight JF. Daytime urinary incontinence in primary school children: a population-based survey. The Journal of Pediatrics. 2000;137(6):814-8.
29. Heron J, Grzeda MT, von Gontard A, Wright A, Joinson C. Trajectories of urinary incontinence in childhood and bladder and bowel symptoms in adolescence: prospective cohort study. BMJ Open. 2017;7(3):1-9
30. D'Ancona CA, Lopes MH, Faleiros Martins AC, Lúcio AC, Campos RM, Costa JV. Childhood enuresis is a risk factor for bladder dysfunction in adult life?. Neurourology and urodynamics. 2012;31(5):634-636.
31. Ching CB, Lee H, Mason MD, Clayton DB, Thomas JC, Pope IV, JC, Adams MC, Brockill JW, Tanaka ST. Bullying and Lower Urinary Tract Symptoms: Why the Pediatric Urologist Should Care about School Bullying. The Journal of Urology. 2015; 193:650-654.
32. Joinson C, Herron J, Butler U, von Gontard A, & The Avon Longitudinal Study of Parents and Children Study Team. Psychological Differences Between Children With and Without Soiling Problems. Pediatrics: Official Journal of the American Academy of Pediatrics. 2006; 117:1575-1584.
33. Joinson C, Heron J, von Gontard A, Butler U, Golding J & Emond A. Early Childhood Risk Factors Assoicated with Daytime Wetting and Soiling in School-age Children. Journal of Pediatric Psychology. 2008; 33(7):739- 750.
34. Filce HG, LaVergne L. Absenteeism, education plans and anxiety among children with incontinence and their parents. Journal of School Health. 2015; 85(4).
35. National Disability Insurance Agency. National Disability Insurance Scheme Pricing Arrangements and Price Limits 2021-22. 2021. Accessible from: https://www.ndis.gov.au/providers/pricing-arrangements [Accessed 2021 November 19]
36. Australian Government Department of Health. Commonwealth Home Support Programme (CHSP) – Payment in Arrears and Unit Pricing – October update. 2021. Available from: Commonwealth Home Support Programme (CHSP) – Payment in Arrears and Unit Pricing – October update (health.gov.au) [Accessed 2022 February 22]
37. Australian Nursing and Midwifery Federation (Victorian Branch). Nurses and midwives (Victorian Public Sector) (Single interest employers) enterprise agreement 2020-2024. 2020. Available from: 200120-NandM-EBA-master-clean.pdf (anmfvic.asn.au) [Accessed 2022 February 22]
38. Victorian Hospitals Industrial Association. Allied health professionals (Victorian public sector) single interest employers enterprise agreement 2020-2021. Available from: Allied_Health_Professionals_Victorian_Public_SectorSingle_Interest_Employers_Enterprise_Agreement_2020-2021.pdf (easternhealth.org.au) [Accessed 2021 November 19]
39. Lawford BJ, Bennell KL, Hinman RS, Morello R, Oliver K, Spittle A. Participant Experiences with National Disability Insurance Scheme Funded Allied Healthcare Services During COVID-19. The University of Melbourne, the National Disability Insurance Agency with funding from the Melbourne Disability Institute. 2021. Melbourne, Australia.
40. Thompson J. Professional profile and workforce issues of nurse continence specialists in Australia. Australian and New Zealand Continence Journal. 2019;25(2):45-49