



Submission to the Australian Government Department of Social Services Public consultations for the NDS and NDIS Outcomes Frameworks

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Background

The Continenence Foundation of Australia made a written submission on the National Disability Strategy 2020-2030 (NDS) and National Disability Insurance Scheme (NDIS) outcomes frameworks. The aim is to help governments understand how to better measure and report outcomes for people with disability. The Foundation provided feedback to the consultation via an online guided questionnaire.

Improving outcomes for people with disability

1. What matters most to measure and report on as we seek to achieve inclusive and accessible communities for people with disability?

Proposed Indicators –

1. I can access public spaces and participate in social and community activities.
2. Built and natural environments are accessible.
3. Family/carer relationships

Proposed Measures –

Increase in number of public facilities contributing to universal design across jurisdictions:

- Changing Places
- Adult Change facilities
- BINS4Blokes
- Stoma changing facilities

During the Stage 2 consultation of the National Disability Strategy, the Continence Foundation of Australia (the Foundation) supported improved implementation of universal design principles. Applying these principles to all public spaces will ensure access to and participation in social and community activities and support family/carer relationships. Therefore, the Foundation proposes the above indicators and measures to be implemented to ensure inclusive and accessible communities.

Changing Places and Adult Change facilities both promote principles of universal design and provide similar levels of support for people living with a disability. A 2019 Changing Places survey stated users living with a wide range of disabilities including autism, para/quadruplegia and intellectual disabilities found the facilities to be necessary services. Incontinence was frequently cited as a reason for needing to use the facilities.¹ In the 2016 Changing Places survey, 75% of respondents said they would use or would assist someone else in the use of a Changing Places facility.² Carers and care workers made up two-thirds of respondents highlighting the high level of community support for the facilities as a best practice example of practical inclusiveness.

Complementary initiatives, Stoma changing facilities and BINS4Blokes (campaign promoting implementation of disposal bins for incontinence products) are already incorporated into the Changing Places and Adult Change facilities design³⁻⁵ further promoting inclusivity, accessibility, dignity and independence.

2. What is most important to measure and report on as we seek to achieve economic security for people with disability?

Proposed Indicators –

1. Financial stress/access to emergency funds
2. Economic independence

Proposed Measures –

- Nationally consistent funding levels for continence assessments not confined to a one-off episode but rather based on needs
- No cap on continence-related funding for both NDIS and non-NDIS participants.
- Measuring workforce participation by people with severe incontinence
- Access to emergency funds during natural disasters, declared state of disasters, health pandemics.

For many people, incontinence is a chronic condition and loss of bladder and/or bowel function is recognised as a disability under the Disability Discrimination Act 1992.

Acknowledging people with disability are more likely to have lower financial independence, the Foundation stresses the need to have **appropriate funding arrangements to protect individuals against financial stress, in times of emergency and to maintain economic participation and independence which are vital to maintain quality of life.**

For most people of working age, participation in paid employment is the means to economic security, yet incontinence negatively affects employment levels. Evidence indicates that persons

with slight, moderate and severe incontinence are 13%, 16% and 50% less likely to be employed than those in the general population with a disability aged 15 to 64 years⁶ meaning they are more likely to be under financial stress and have lower economic independence. Need for assistance with bladder or bowel control appears to be a key contributor to low labour force participation, at only 20.4% for people who always or sometimes needed assistance, compared with people who had difficulty but did not need assistance (42.3%) and people who had no difficulty at all (56.8%).⁷ In recognition of this, the Foundation recommends all work-related impairments currently considered for disability support pension eligibility should be part of workforce participation outcome measures.

Due to variable understanding by planners of the importance of comprehensive continence assessments, there is major inconsistency in how capacity building support funding is allocated to continence assessments nationally. There is still a problem of some participants not having continence supports included in their plan at all, although this is improving. A lack of appropriate continence-related supports included as health-related disability supports adds further financial strain for people living with disability and their carers, increasing stress and lowering independence.

In some plans, continence assessments are not confined to a one-off episode of capacity building support and services can be charged for longer periods if required. In other plans, continence assessment funding is more prescriptive: varying from 4-6 hours in Melbourne but only 3 hours in parts of rural Victoria and reports of just 2 hours in Queensland. This may be inadequate if the participant's disability related health care is complex or for any travel requirements by the Nurse Continence Specialist. It means participants may lack the appropriate continence care they need and may result in higher costs associated with inappropriate purchases or long-term overdependence on continence products.

A lack of appropriate budget in NDIS plans for continence assessment, products, and bladder and bowel management such as toilet training can contribute to poorer quality of life for participants and lower participation rates in social and economic activities. No other reasonable and necessary disability support has this type of capped time and funds allocated. There should be no cap on funding for participants, but where derived from Nurse Continence Specialist reports, they may be individualised to ensure appropriate levels of continence-related funding are available to use based on their needs.

3. What is most important to measure and report on as we seek to achieve health and wellbeing outcomes for people with disability?

Proposed Indicators –

1. Access to health services
2. Early intervention

Proposed Measures –

- Incidences of funding for specialist continence assessments where continence products are part of an NDIS plan
- Reduction in long-term continence product use associated with early intervention through capacity building supports to promote, establish, and maintain continence.

Incontinence is a diverse, complex issue at the intersection of health and disability. Incontinence can affect most of the proposed indicators in the consultation paper including mental, physical, sexual and reproductive health and aged care support. The Foundation argues its importance must be acknowledged as relevant across the health and wellbeing domain. Accordingly, the Foundation

proposes a greater focus on access to specialist continence services to maximise health and wellbeing across the disability sector, especially the NDIS.

Incontinence is a significant issue for people with disability. There are an estimated 316,500 Australians living with both incontinence and disability.⁷ For NDIS participants, there is little information about appropriate pathways to specialist continence clinics who can assess, diagnose and provide support plans for participants. Following the major policy change to include some disability-related continence supports last year, it is estimated 40-60,000 participants require re-assessment in light of the change. The Foundation is well placed to participate in any project funded by the NDIA to provide specialist expertise and guidance to create a continence support participant pathway to address real concerns about participant health and wellbeing. At a minimum, participants should be advised of the availability of the National Continence Helpline which will contribute to greater rates of referral for specialist continence assessment and early intervention.

The Foundation contends that greater access to both specialist comprehensive continence health assessments and capacity building supports are necessary to deliver improved outcomes. In line with this, the Foundation maintains funding for specialist continence assessment is necessary whenever funding for continence products is part of participant's NDIS plan. The Foundation also contends a comprehensive continence assessment is necessary to recommend funding for capacity building supports to promote, establish and maintain continence. This will enable better treatment, management and cure where possible promoting higher quality of life and reduce overdependence on continence products.

4. What is most important to measure and report on as we seek to achieve rights, protection, justice and legislation outcomes for people with disability?

Proposed Indicators –

1. I am not discriminated against because of my disability

Proposed Measures –

- Disability-related discrimination
- Disability-inclusive emergency planning

Incontinence is a stigmatised condition and people living with incontinence are subject to both direct and indirect discrimination. For example, many people try to hide their incontinence, especially in workplaces for fear of discrimination and people are less likely to consider functional impairment causing incontinence as a disability under the Disability Discrimination Act 1992. Recognising this, the Foundation affirms its belief that disability-related inclusion, and disability-inclusive emergency planning are of vital importance as baseline measures to protect and support all people living with incontinence.

Over the course of the past year, Australia has faced both extreme levels of bushfires and a global pandemic. This has exposed a rift between service provision for people with a disability and people without, such that the Disability Royal Commission has stated people with disability have been 'forgotten and ignored' during the pandemic.⁸

To address these issues, the Foundation asks all Australian Governments (federal, state, territory and local) to work together and adopt disability inclusive disaster risk reduction principles (DIDRR) to address the needs of people with disability in Australia during natural disasters and pandemics.⁹ Specifically, we ask governments to recognise that people living with incontinence experienced

barriers in access to health care, sanitation and hygiene as a consequence of policy directives and government actions including those experienced during the lockdown of the Melbourne public housing towers. Additionally, they should also guarantee supply and act as or to commission a supplier of last resort to maintain access to continence products and services. Taking these steps will result in governments addressing access to continence care and continence products as a human rights issue and reduce disability-related discrimination for people living with incontinence.⁹

5. What is most important to measure and report on as we seek to achieve learning and skills outcomes for people with disability?

Proposed indicators -

1. School attendance

Proposed measures -

- Number of instances of school absenteeism due to incontinence
- Number of instances of school absenteeism due to lack of access to toilet facilities or assistance with toileting or continence management

Incontinence and related issues can impact participation and engagement in formal learning settings. Evidence shows that school toilets can have a negative impact on a child's physical and psychological health with many children avoiding using school toilets for reasons such as smell or physical standards leading to bladder and bowel issues.¹⁰ Children with incontinence are more likely to experience bullying and to have higher absenteeism.¹¹⁻¹⁴ Anecdotally, parents report their children with incontinence are more likely to miss out on educational opportunities such as excursions and school camps.

Learning and skills outcome measures should include the number of formal education days missed due to incontinence, lack of access to toilet facilities or to assistance with toileting or continence management.

6. What is most important to measure and report on as we seek to achieve personal and community support outcomes for people with disability?

Proposed Indicators –

1. Person-centred practice
2. Coordination between disability supports and other services

Proposed Measures –

- People with disability feel adequately supported by continence services and supports
- Effective coordination of services and supports including continence clinics

The health and wellbeing of people living with incontinence and other disabilities must be addressed as part of a coordinated and effective system of services and supports. The *Joint Standing Committee on the NDIS* noted funding disputes around service boundaries between the NDIS and mainstream health services can lead to reduced or no access to required services. This has also been noted by experienced disability Nurse Continence Specialists about access by NDIS participants to continence clinics in Victoria. The Foundation contends greater coordination between disability

supports and other services must be complemented by recurrent program funding for system navigators, assisting people with disability, their carers and supporters to successfully address their needs across the six domains of the Strategy.¹⁵

The Foundation has significant concerns about people with incontinence feeling adequately supported by continence services to enable effective and person-centred practices in the disability sector. There is anecdotal evidence of a limited number of qualified Nurse Continence Specialists limiting access to participants. In New South Wales, there are three NDIS registered Continence Nurse Specialist providers for the entire state. With no clear continence support NDIS participant pathway due to lack of registered providers, many continence assessments are still being conducted by State/Territory health services outside of the NDIS. A lack of suitably qualified Nurse Continence Specialists contributes to allied health professionals or nurses not qualified or experienced in continence health undertaking continence assessments, leading to poorer continence assessments and subsequently poorer person-centred continence care.

7. How often would you like to see progress against the outcomes for people with disability in the National Disability Strategy and the National Disability Insurance Scheme reported?

A progress report every two years would be sufficient to review progress against the outcomes for people with disability in the National Disability Strategy and the NDIS. Furthermore, specific reports into each domain, including health and wellbeing, should be made available on a regular basis. This would enable a higher level of accountability, cooperation and collaboration between government and non-government organisations and health peak bodies, like the Foundation, on how ongoing developments within the health and disability sector are being adequately reflected in the access to and effectiveness of services and supports. In saying this, the Foundation expresses its concern that despite the same target being set under the previous Disability Strategy 2010-2020, only one progress report had been presented in the first seven years of the Disability Strategy.¹⁶ Acknowledging this, the Foundation wishes to press all Australian Governments to commit to meeting the 2 year progress report target, as anything longer would be inadequate given the amount of progress needed to be made. This is a means to maintaining a minimum obligation to people with disability, the disability sector and all relevant stakeholders.

8. Is there anything else that you think should be considered when we are monitoring and measuring the impact of activities on people with disability?

Proposed Measures –

- Nurse Continence Specialists (categorised as Clinical Nurse Consultant) must be recognised as conducting comprehensive disability related health support continence assessments, not just continence aid assessments under the NDIS
- Nurse Continence Specialists should be reimbursed for comprehensive disability related health support assessments at the same level of funding as an allied health professional

Under the NDIS, Continence Nurse Specialists are not recognised as providing the same level of disability related therapeutic outcomes for participants as allied health professionals. As a result, *Provision to a participant of continence aids assessment, recommendation, and training support* can only be charged at the Registered Nurse (RN) rate of \$124.05 per hour as opposed to physiotherapists who are able to charge \$193.99 using the line-item *Assessment, Recommendation, Therapy or Training (including Assistive Technology) – Physiotherapy* according to the NDIS Price

Guide dated 1 July 2020. In order to fund a Clinical Nurse Consultant at the rate of \$146.72 for conducting a comprehensive continence health assessment, a participant must have sufficient capacity building supports in their plan for access to a Nurse Continence Specialist, rather than just an RN. Monitoring of the recommended continence management plan is also required more frequently than at annual plan review.

A lower fee structure from the NDIA contributes to making services unsustainable and subsequently ceasing operations. This has also resulted in limited access to Nurse Continence Specialists due to the financial risks and limitations of being a NDIS Registered Provider. Many public health services have chosen not to become NDIS Registered Providers for continence assessments because of these risks. Another unintentional consequence of a lack of qualified services is instances of unqualified staff and consequently poor-quality assessments and recommendations leading to poorer participant continence health outcomes and higher long-term costs.

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