# Submission to the Joint Standing Committee on the National Disability Insurance Scheme – Independent Assessments

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## a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;

The Continence Foundation of Australia (the Foundation) recognises contracting independent health professionals to assess eligibility and functional status of participants in the NDIS can provide accurate reports of individual functional capacity. Having independent assessors specifically trained in NDIS requirements may result in cost and time savings due to reduced delays and costs in making applications, decreased number of reviews and ensuring compliant assessments.

However, the Foundation considers the development, modelling, reasoning and justifications for the introduction of independent assessments into the NDIS is flawed on multiple levels:

- The origins of the idea to apply independent assessments within the NDIS, which lie in no-fault accident compensation schemes, is limited[1]:
    - Accident compensation schemes, and the related functional assessments, are designed to address three types of severe acquired disabilities: spinal cord injuries, acquired brain injuries and severe burns, not any and all types of disability.
    - Functional assessments are designed to drive rehabilitation, not be driven by capacity building and individual goals which is a central aim of the NDIS.
    - No functional impairment tools have been shown to be reliable measures to determine reasonable and necessary funding for all impairment/disability types.
- Despite pointing to the Productivity Commission inquiry report into Disability Care and Support (2011) and the Tune Review (2019) for justification in introducing this new assessment model, neither truly supported the current model's implementation:
    - The Tune Review clearly states that functional capacity assessments would not always be required.[2]
    - The Productivity Commission states the 'assessment process would draw upon existing medical reports' rather than solely on independent assessments.[3]

- Utilising independent assessments shifts the onus of responsibility for assessment outcomes onto assessors and participants.
- Reviewing participant abilities and challenges within a three-hour period, likely is not enough time to understand the full functionality of an individual in one setting let alone the multiple settings they will engage in.
- The assumption the participant or prospective participant can outline their individual needs within three short hours is problematic. Even more so for many who find it difficult to speak about their condition. Incontinence, for example, is stigmatised[4] and speaking openly about the issue and its consequences can be difficult if not embarrassing.
- It is not yet clear how the various assessment tools will be combined to assess the individual particularly as the tools were not designed to be combined.[1]
- Neither of the two pilots reviewing independent assessments evaluate the validity of the independent assessment or the resource allocation.[1]
- Administrative efficiency over effective assessment reviews is being prioritised. This can lead to ongoing issues related to insufficient funding and inaccurate supports being put in place resulting in neglect and unnecessary harm.
- An assessment process that measures a person at their best will not allow for adequate support to be provided when they are below their best.

### b. the impact of similar policies in other jurisdictions and in the provision of other government services;

The aged care sector underwent a significant change with the introduction of the Aged Care Act 1997. It focused on developing a cost-efficient aged care sector however it has had a number of consequences, as identified in the Royal Commission into Aged Care Quality and Safety's final report. The report stated '*the 1997 changes effectively 'enabled cost savings through replacement of nursing staff with care workers', and has resulted in compromised care for older people in residential care'*.[5] It goes further to say that the 'current Aged Care Act is focused on the financial relationship between the Australian Government and the providers, and, in particular, on restraining expenditure rather than on the rights of older people to the care that they need.'

The Foundation believes in the same way introduction of the Aged Care Act 1997 stripped away the quality of care provided by decreasing health expertise and care quality. Independent assessments risk reducing the quality of assessment and focus on the individual needs of prospective and current NDIS participants. The long-term consequences in resource allocation due to independent assessments could be similar to what has occurred in the aged care sector. Utilising independent assessments which narrowly focus on functionality and not health, social or economic factors can lead to disability supports narrowly focused on rehabilitation, not capacity building.

### c. the human and financial resources needed to effectively implement independent assessments;

The Foundation believes a flawed independent assessment process will not provide the level of human and financial resources needed to effectively implement independent assessments. Incontinence, for example, will not be addressed fully as part of the independent assessment process and this is unlikely to be mitigated with any level of human and financial resources being made available by the NDIA.

Incontinence and its impact on participants has largely been excluded from the proposed independent assessments. However, considering incontinence can occur on an intermittent basis, be spontaneous, severe, embarrassing, highly impactful on quality of life, affect mental and physical health, it can only be properly addressed with specific, recognised best practice assessment. The training to become an independent assessor is not transparent, nor publicly available, so it is not known whether there is any additional benefit from this for people living with incontinence. The Foundation has serious concerns that this will not translate into safe and effective continence supports for NDIS participants.

The Foundation questions whether the NDIA will drive agility within the independent assessor workforce as well as in the distribution of financial resources to respond to changing needs. For example, following the major policy change to include some disability-related continence health supports in 2019, it was estimated 40-60,000 participants required re-assessment. The Foundation is also aware through our work with NSW Ministry of Health, that there are skills shortages in the provision of high-risk disability-related health supports under the NDIS, including catheterisation and bowel care, creating significant health risks for participants. Assessments conducted by independent assessors with minimal or no training in safe and effective continence supports, and/or have a lack of knowledge in these changes, will result in participants receiving suboptimal support.

The Foundation is well placed to participate in any project funded by the NDIA to provide specialist expertise and guidance to facilitate access to the human and financial resources for comprehensive continence assessments to address real concerns about participant continence health and wellbeing.

### d. the independence, qualifications, training, expertise and quality assurance of assessors;

The Foundation queries the qualifications, training, expertise and quality assurance of independent assessors in relation to continence support needs. In Australia, there were an estimated, 316,500 people experiencing incontinence and an additional disability in 2009.[6] Recent data from the Continence Foundation of Australia National Surveys shows a significant increase in the number of people with disability reporting incontinence (23% to 31%) between 2017 and 2020.[7-8] 91.0% also had a severe or profound core activity limitation, indicating they had high-support needs.[6] The high incidence of incontinence in people with disability shows continence support is a key day-to-day need that must be addressed by the independent assessor as it is only then that it will translate into sufficient financial resources for disability-related health and capacity building support.

The Foundation is concerned the potential independent assessors, such as occupational therapists, physiotherapists and psychologists who may not fully comprehend the impact of incontinence and range of supports required, are unlikely to ask the right questions to address this impact. Specific questions from proposed assessment tools like ‘Can you toilet by yourself?’ do not capture other complex issues such as impact, frequency and differences in the experience of incontinence due to changes in the setting. Therefore, a person-centric assessment is unlikely to occur as a result. Given the guidance from the assessment tools and the expected level of expertise in continence from the nominated occupational roles, people experiencing incontinence will likely be left behind at the assessment phase.

Stigma is a key concern when it comes to addressing incontinence in the assessor-participant interaction. A recent US survey of people experiencing incontinence found 30% were too embarrassed to discuss their concerns with their primary care physician.[9] A Continence Foundation of Australia nationally representative survey (2020) found that only 17% of respondents had ever discussed incontinence with their GP but only in one six of those conversations were raised by the GP themselves.[8] Considering this, and the fact that the suite of independent assessment tools do not cover incontinence adequately, concerns about incontinence during assessor-patient interactions may not only be ignored but avoided, even when knowledge of it is apparent.

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.[10] 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 following were the key findings[10]:

- 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 yearly costs of consumable products for continence (e.g., continence pads) by $3614.80 per person per year.
- Improved participant independence in activities of daily living, three months after implementation.

The value of a comprehensive continence assessment by a qualified continence expert in reducing costs and increasing independence has been clearly demonstrated.

It would be appropriate therefore to have nurse continence specialists involved in independent assessments or, at the very least, where incontinence is recognised, all NDIS participants should also have funding for a comprehensive continence assessment by a nurse continence specialist to ensure all participant continence support needs are addressed.

### e. the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding;

The Foundation believes the process to consult with stakeholders on the appropriateness of the assessment tools selected has not been transparent. While the NDIA have named the tools they intend to use, they have not provided easy access to the tools for public scrutiny. The assessment tool suite, in their full form, don't appear to be available on the NDIA website or relevant documentation and they are also difficult to access from other resources, including other websites. The versions being proposed could also have been adjusted for the Australian disability community so any version found elsewhere could be different and therefore unreliable in understanding what is being proposed. This goes directly against the recommendations in the Tune review (2019) which states that the NDIA should be providing 'clear and accessible publicly available information, including on the NDIS website, on the functional capacity assessments being used by the NDIA and the available panel of providers'.[2]

From the limited information that can be gathered independently of the NDIA, only the Vineland 3 Domain Version appears to directly measure continence-related issues including urinating or defecating in a toilet or potty chair, using the toilet when needed without help, confirmation of toilet training, and mention of toileting 'accidents'. However, these questions do not highlight the overall impact of incontinence on an individual's functionality. For example, it does not collect information on how a participant's incontinence can impair educational, social and economic participation.

The Participation and Environment Measure- for Children and Youth (PEM-CY), WHODAS 2.0 36, the Lower Extremity Function Scale (LEFS) and the Craig Hospital Inventory of Environmental Factors

(CHIEF) questionnaire do not mention continence directly but can be utilised to measure it indirectly. Whether this occurs will depend on the individual assessor's knowledge, skills and experience relating to incontinence and the participant's willingness to address incontinence concerns freely.

The full form of the Pedi-CAT or the Pedi-CAT ASD was not able to be accessed during the research phase of this submission and so no comment can be provided for it except for the fact that, once again, it is highly unlikely that continence needs are adequately addressed in this tool.

### f. the implications of independent assessments for access to and eligibility for the NDIS;

As the Foundation outlined in response to the first term of reference (a.), there are potential benefits to having a disability neutral suite of assessment tools in theory. However, as it has been outlined, there are no currently available tools that directly and precisely map to all International Classification of Functioning, Disability and Health framework domains.

In addition, the focus on the functional aspects on their own is limited. The Tune Review clearly states that while standardised functional capacity assessments will improve the quality and consistency of NDIA decisions, they would not always be required.[2] The 2011 Productivity Commission Inquiry report on Disability Care and Support stated that it would still be important to involve people familiar with the care and support of the needs of the individual, including family, carers, and direct support professionals alongside existing medical reports.[3] This second point appears to be limited under the proposals provided in the *NDIA's Independent Assessment Framework* (2020) document. However, it would allow for a more holistic assessment of participants and translate into more personalised funding and supports.

The NDIA have also argued in their *Independent Assessment framework* paper that it is better to get an approximate answer to the right question, rather than an exact answer to the wrong question by utilising functional assessments over inconsistently applied but disability specific assessments. While this has some merit, the argument cannot then be made that this would translate into a personalised plan and budget[11] if the outcome of the review is expected to be, not personalised, but vague. This has significant consequences for all participants within the NDIS. It will be far better to create a person-centric model of assessment rather than utilise a standardised set of indicators focused on function alone.

### g. the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports;

Independent assessments will have a range of implications for participant engagement. While this may result in more efficient, timely and financial benefits (due to the provision of the assessment at no cost), it is not clear how this will facilitate more personalised NDIS planning and decisions related to funding reasonable and necessary disability supports.

Neither of the two pilots reviewing the independent assessments evaluate the validity of the independent assessment or the resource allocation.[1] The results provided instead evaluate the participant's perception of the appointment itself including length of appointment or satisfaction with the assessor selected for them which are not relevant to understand the overall consequences. It is also not clear how the various assessment tools will be combined to assess the individual[1] which means the judgement by independent assessors can be questioned, and their decision-making may not be effective in understanding the functional capacity of participants.

It has not been made clear how the independent assessments will assess the relationship between a participant's disability and function. As such, the functional assessment will only be as good as the expertise of the assessor, the ability of the participant to provide information in a timely manner and if adequate time is allocated for assessment to be conducted, data collected and report completed. For participants living with incontinence, the skills, knowledge and experience the independent assessor has in relation to incontinence and its impacts will determine the need for funding reasonable and necessary supports. Otherwise, it can easily be disregarded by the assessor as unimportant. Despite this, the impact of incontinence can have significant implications on an individual's function. In addition, while experiencing incontinence has been linked to significantly worse functional disability scores[12], gaining a single snapshot of functionality will not allow for linking between all aspects of incontinence and function. In turn, this could result in a misunderstanding of the types of support required in both the short and long-term which should logically make the assessment invalid. If independent assessments are the main method that will facilitate planning, funding and support, the complexity and importance of even mild incontinence as part of a participant's life will be ignored to the detriment of their quality of life.[13] Without this, individuals may not receive the safe and effective continence supports they need as NDIS participants.

### h. the circumstances in which a person may not be required to complete an independent assessment;

The NDIA has outlined two reasons for not needing to complete an independent assessment:

- When the process is more likely to do more harm than benefit, and
- Where there are concerns about the process producing valid information and other sources and/or forms of information are better suited.

As the Foundation has highlighted previously, the suite of independent assessment tools are inadequate in measuring incontinence in terms of its impact on function, but also neglect the ongoing needs of participants living with incontinence and this is unlikely to translate into safe and effective continence supports under the NDIS. Incontinence can be unpredictable, varying in degrees of severity over time and progress or deteriorate over time with identified links across a number of co-morbidities all of which impact the participant's life, including but not limited to function. Thus, where a comprehensive continence assessment can identify the link between a participant's incontinence and their function, among other things, it will represent valid information that cannot and should not be ignored by the NDIA. This will likely be the case for many participants who have had a long and recognised history of disability including chronic incontinence.

Furthermore, the fact that the independent assessments may not be able to take into account all of the environments and interactions that people with disability engage with on a daily basis, it is incumbent on the NDIA to recognise the selected assessment tools are inadequate and must be co-designed with stakeholder engagement.

### i. opportunities to review or challenge the outcomes of independent assessments;

Participants must be able to challenge the outcomes of independent assessments based on all of the information and expertise they have at their disposal. However, it appears that the NDIA have chosen to minimise potential for asking decisions to be reviewed. The NDIA have stated in their *Access and Eligibility Policy with independent assessments consultation paper* that 'applicants can only seek a second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances'. Delegates appear to have complete discretion over granting exceptions from an independent assessment, meaning many participants may miss out on appropriate and comprehensive continence assessments from qualified healthcare professionals.

The NDIA's approach to reviews or challenges of independent assessment outcomes, goes directly against the recommendations of the Tune Review. The Tune Review recommended that participants having the 'right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment or seek some form of arbitration if, **for whatever reason**, they are unsatisfied with the assessment'.[2]

Participants should be allowed to utilise appropriate specialist assessments such as continence assessments from qualified nurse continence specialists to review or challenge assessment outcomes from independent assessors. This will depend on who makes the initial assessment, their qualifications and expertise in continence support as well as their method of assessment including the tools they utilised.

### j. the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds;

Each independent assessment tool must be appropriate to evaluate particular cohorts of people with disability. This means that, where relevant, the assessment and assessor must utilise simplified language that is cohort-centric. If this is not possible, it would be appropriate for an interpreter to be present so the participants can provide informed consent, accurate feedback and discuss issues that are relevant to them. However, considerations must be given to known barriers within Aboriginal and Torres Strait Islander communities such as embarrassment for the participant and interpreter (whom in most cases would know each other) and gender differences between professionals and participants.[14]

It is unclear what training the assessors received as part of the pilots and how applicable this is to particular cohorts so the appropriateness of assessor expertise, knowledge and capacity is certainly of concern here alongside the assessments.

For many participants in regional, rural and remote areas, the implementation of telehealth will be inappropriate because the assessor will have to rely on an even more restricted experience (a screen as opposed to being in the same room) to assess the participant and so telehealth should be used only when another professional is physically present with the participant or as an option of last resort. Face to face assessments should be the norm throughout Australia as otherwise this could significantly worsen assessment quality and outcomes.

### k. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability; and

As highlighted previously, the Foundation considers incontinence will not be appropriately assessed with this suite of assessment tools and this will likely not change for people with incontinence and psychosocial disability either. Incontinence is a complex condition sharing many characteristics with mental health issues: characteristics related to age, gender and other demographics cannot profile either condition. Furthermore, they can be hidden conditions making it difficult to 'assess' based on a set of assessment tools that simply focus on functionality rather than disability.

The relationship between incontinence and mental health is not well understood or acknowledged within wider health and mental health sectors. An Australian study found a significantly higher rate of depressive disorders in people with urinary incontinence (21%) compared to those without (14%).[15] Likewise, a review of global studies found people with incontinence had a 6 to 43% likelihood of comorbid depression.[16] While depression and incontinence both reduce quality of life independently, when they occur together, there appears to be an additive effect on both physical and mental health.

This means that the overall effect of ignoring either, or worse both, will likely have an added detrimental effect on the participant's life as they will not be adequately supported for either.

### l. any other related matters

The Foundation considers expertise of Nurse Continence Specialists and the complexity of the continence assessments they undertake for people with disability is being overlooked within the independent assessment process. Nurse Continence Specialists 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.

A Nurse Continence Specialist is critical to ensuring best-practice continence care and management of incontinence. Wagg and Colleagues (2014) 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…There is evidence that patients appreciate the communication skills and comprehensive continence care provided by nurses*'.[17] Therefore, it is essential that the key role of Nurse Continence Specialists is recognised in the NDIS Independent Assessment process, to address real concerns about participant health and wellbeing to enable higher quality assessments and subsequent disability related health supports.

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