Occupational Therapy AUSTRALIA

Ms Bonnie Allan
Committee Secretary
Joint Standing Committee on the NDIS

Via email: NDIS.Sen@aph.gov.au

21 May, 2021

Dear Ms Allan

Re: Occupational Therapy Australia response to question taken on notice at public hearing in Melbourne on 23 April 2021

Occupational Therapy Australia (OTA) thanks the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for the opportunity to appear before the Committee on 23 April 2021, and to respond to the following question from Senator Carol Brown taken on notice at the hearing:

> *Do you see the tools that have been selected by the NDIA – such as the WHODAS and PEDI-CAT – as being appropriate measurements to inform a funding decision in a NDIS plan?*

OTA holds a clear position that people with a disability in Australia have a right to an evidence-based, robust, and safe process for assessment of functional capacity to determine access to the NDIS, and to determine funding for reasonable and necessary supports. For this reason, OTA welcomes Senator Brown's question regarding the appropriateness of the tools selected by the NDIA to inform NDIS plans and funding decisions.

OTA has considered the relative merits and limitations of the Independent Assessment (IA) measurement tools proposed to inform funding decisions and NDIS plans. This includes close examination of their relevance, utility, and psychometric properties (WHO 2020).

While these tools have reasonably sound intrinsic measurement properties when used for the purpose for which they were specifically designed, their reliability and validity is profoundly compromised when they are used for other purposes. OTA does not believe the NDIA is using the measures for the purpose for which they were intended. These tools were not designed to specifically assess functional capacity to inform funding decisions or plans, and they lack sufficient relevance, sensitivity or specificity to be used in this way.

OTA offers the following specific observations in response to Senator Brown's question.

Are these tools designed to sufficiently inform funding for NDIS plans?

The IA toolkit is primarily based on the use of global self-report measures related to levels of health and disability in the general population. They have reasonably sound measurement properties when they are used for their intended purpose. However, they are not designed as functional assessment tools and do not provide sufficient detail to effectively determine individual functional capacity or support needs.

A functional assessment identifies what the person can and can't do, due to disability-related impairment. A support needs assessment identifies what the person needs to address the impairment, so that they can capacity-build, or compensate for the impairment, thereby reducing the impact of the disability on their ability to participate in their lives and community. Delivering standard plans and budgets, sometimes known as 'roboplans', based on an IA provides limited detail and effectively bypasses the essential step of individual support needs identification. By neglecting disability support needs, the NDIA runs the real risk of rendering the assessment process more costly in the long term, both in terms of human suffering and dollar amounts. OTA recommends support-needs identification be an essential step in the determination of participant plans and the budgets that support them.

Are the IA standardised assessment tools INDIVIDUALLY appropriate to inform funding decisions for NDIS plans?

The individual assessment tools included within the pilot IA, are robust tools when used for their intended purposes. These are summarised in Table 1. None, however, was developed for the purpose of determining NDIS participant plan budgets. Each tool has evidence-based validity when used with the particular cohorts they were designed for. However, they cease to be valid when they are used with other cohorts. Apart from the WHODAS-2, none was developed to be used in a 'disability neutral' manner.

The WHODAS-2 is a global measure of based on the conceptual framework of the International Classification of Functioning, Disability, and Health (ICF). While the WHODAS-2 can be used across all disability cohorts, it is a functional screen only, not a functional capacity assessment (Ustun et al 2010). For example, it is entirely possible for a person to have substantially reduced capacity for self-care, and for this not to register on the WHODAS-2.

Attempting to use specific IA tools in a disability neutral manner, is problematic in practice. For example, the Vineland 2, a measure of adaptive functioning, has proven validity when used with people who live with developmental disability, such as autism, intellectual disability, or attention-deficit hyperactivity disorder. The Vineland 2 does not have proven validity to assess people with degenerative conditions, or those who live with psychosocial disability where capacity fluctuates over time. The NDIA intends the Vineland-2 to be used with all NDIS applicants and participants, including cohorts the tool has not been validated for. The current IA pilot espouses this practice. The company publishing the Vineland-2 is aware of the limits of its proven validity, and states that the 'burden of proof' for appropriate use of the tool sits with the NDIA and NDIA-contracted companies. So, we have a situation

whereby participants are undergoing a lengthy, deficit-focused assessment, which is not a valid tool to use with a large proportion of those participants and which will result in flawed scores being used to inform funding decisions in NDIS plans.

The Care and Needs Scale (CANS) was specifically developed for use with people living with acquired brain injury, and was not developed to be used uniformly across all disability cohorts. Therefore, it cannot reliably inform funding decisions for all NDIS participants.

The PEDI_CAT is a norm-referenced deficit focused self-report measure that parents complete on behalf of their child (Haley et al 2011). The tool measures the extent of a child's functional delay in relation to normal age-related milestones. The tool lacks sufficient detail to specifically determine the individual functional or support needs of a child and, crucially, it fails to measure their functional potential. For these reasons, this tool has limited usefulness in determining funding for NDIS plans.

TABLE 1: IA Assessment Tools

Assessment Tool	**What does it measure?**	**Compatible with NDIA -intended 'disability neutral' approach (a uniform assessment across all disability types)**	**Evidence that the tool can reliably assess functional capacity to inform NDIS funding decisions**
WHODAS 2	Functional capacity	Yes	None
CHIEF	Environmental factors- not functional capacity	Unclear e.g. not researched or validated with people with psychosocial disability	None
Pedicat	The extent of a child's functional delay in relation to normal age-related milestones – not functional capacity	Unclear. Designed for children from 6 months to 7.5 years. Has a greater weighting toward physical disability	None
Vineland 2	Adaptive behavior – not functional capacity	No. Proven valid for use with specific cohorts	None
Care and Needs Scale (CANS)	Care and needs – not functional capacity	No. Proven valid for use with specific cohorts	None

Lower Extremity Function Scale	Lower extremity function – not functional capacity	No. Proven valid for use with specific cohorts	None

Are the IA standardised assessment tools COLLECTIVELY appropriate to determine participant plan funding?

There are fundamental flaws in using the unrelated IA self-report measures collectively to provide an overarching picture of a participant's level of disability (Madden et al 2015). This is because these tools have been developed and validated to measure distinctly different constructs in distinctly different ways. While they may loosely fit under a general concept of disability, they do not collectively measure disability or functional capacity as a construct. They are invalid and meaningless when they are used collectively. The NDIA appears to have chosen this approach to determine functional capacity, and to use this as a basis for disability funding, yet to the best of our knowledge this approach has never been proven effective anywhere in the world. In fact, research indicates the absence of a single assessment tool, or suite of tools, proven to have the capability to do this (Madden et al 2015).

To validate the NDIA's proposed IA as a basis for participant plan funding, it would need to prove that:

- The suite of assessment tools that constitute an IA can accurately assess functional capacity in a uniform, disability neutral manner;
- The IA can accurately predict participant funding based on the IA score, in the absence of a support needs assessment; and
- Functional capacity can be measured in a 'disability neutral' manner across all cohorts.

Best practice functional capacity assessment is comprised of self-report tools, observational tools, clinical reasoning and interpretation by appropriately skilled clinicians, and the inclusion of carer, participant, and existing provider perspectives and cultural considerations, to triangulate and formulate an accurate assessment of functional capacity. Complete reliance on self-report tools runs a high risk of under or over-rating functional capacity, and is overly simplistic. Basing participant plan funding on an IA grounded in self-report measures is fraught with inaccuracies and bias. Extensive reliance on telehealth to complete the IA with vulnerable or remote cohorts may further compromise the accuracy of this approach.

How will the scores be determined and how will they be used?

There has been a lack of transparency around how the NDIA intends to use the suite of assessment tools collectively to determine participant plan funding. The agency has not revealed how the scores from individual assessment tools will combine to give an overall IA score, or how a suite of IA scores will generate participant plan funding. OTA cannot provide an evaluation of the NDIA process for translating IA scores into a participant budget, for the simple reason that the details of this process have not been disclosed by the NDIA. The mechanism may include a weighting of certain assessment scores against disability type to

define functional capacity, or a formula, or an algorithm – OTA and the sector can only speculate.

OTA would have serious concerns if the NDIA did intend to collate the scores of the IA tools to determine funding decisions for NDIS plans. Generally, detailed factor analysis is required to sum scores in any measurement tool and this is based on the premise that the content and items in the measurement tool are measuring the same construct. It is not possible to sum scores from different measurement tools, as they do not measure the same things in the same way, or to the same extent. If the NDIA intends to sum the scores of IA tools that are distinctly different measures, it is incumbent on the agency to demonstrate that the methods it is using to sum these scores are appropriate and psychometrically sound for the purpose of informing the funding for NDIS plans.

As the IA tools are intended to inform funding decisions related to NDIS plans, OTA requests the Joint Standing Committing seek full transparency around this mechanism, and support the establishment of a process of clinical scrutiny and sector consultation.

Summary

OTA has reviewed the independent assessment tools selected by the NDIA to determine funding decisions in NDIS plans. Through this process, OTA has come to the clear conclusion that the Independent Assessment (IA) tools, used both individually and collectively, are not appropriate measures to inform funding decisions for NDIS plans.

OTA urges the Committee to seek full transparency from the NDIA around the aim of the IA pilot, and recommends that the IA is not implemented until adequate, independent research proves its validity for the NDIA's intended purpose. This research is too important to occur behind closed doors, without independent academic and ethical oversight.

OTA thanks members of the Joint Standing Committee for their continued interest in this most important matter.

Yours sincerely

Samantha Hunter
Chief Executive Officer

References

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