

30 March 2021

SUBMISSION TO JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

INDEPENDENT ASSESSMENTS AND RELATED ISSUES

The risks and value of Independent Assessments in the context of the NDIS cannot be considered in the absence of a consideration of how the Scheme has been implemented to date, and its broader ecosystem - the National Disability Strategy and associated community and mainstream supports. Therefore, in this submission I beg the tolerance of the Joint Standing Committee to allow a short preamble before I proceed to the specific Terms of Reference related to Independent Assessments.

The thoughts I am proposing come from a position as one of the original proponents of the NDIS design, as a member of the Disability Investment Group which recommended the proposal, and an Associate Commissioner of the Productivity Commission report which was supported by the Australian community and both sides of government when released in 2011. I was also a Board member of the NDIS from 2013 to 2020, and Principal Member of the NDIS Independent Advisory Council from April 2019 until July 2020.

The views expressed below are totally mine, and have not been influenced by any associations.

Failure to implement the NDIS and associated ecosystems

Australian governments have persisted with an ideology of welfare and paternalism in limiting the rights, choice and control of people with a disability, leading to a failure to recognise the potential of the National Disability Insurance Scheme (NDIS). The National Disability Insurance Agency (NDIA) has been constrained by a governance model lacking the independence recommended by the Productivity Commission (PC) 2011¹, and also lacking the mechanisms to constructively embed a culture of equitable resource allocation and empowerment and flexibility for participants. Some of these aspirations are now being attempted following the 2019 review by David Tune, but now face many more obstacles due to the mistrust and loss of supportive momentum which have become entrenched throughout the system with the failures over the preceding decade.

These failures have been exacerbated by a lack of constructive Federal cooperation, and mutual indifference and neglect of people with disabilities in the resistance by governments to the development of an ecosystem of community and mainstream supports for all people with a disability. This is manifested through progressively poor implementation and eventual defunding of a dedicated "Tier 2" of the NDIS (Information, Linkages and Capacity Building - ILC), a failed application of Sector Development, failure to fully implement a National Injury Insurance Scheme (NIIS), and above all, the neglected National Disability Strategy 2010-2020 (NDS). Indeed, the expectations of the NDS, so hopeful after the outrage spawned by the *Shut Out Report*², were quickly frustrated as,

¹ <https://www.pc.gov.au/inquiries/completed/disability-support/report>

² <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>

far from expanding their commitment to equal opportunities and rights in health, education, justice, housing and other mainstream services, governments took the opportunity of “in-kind” NDIS contributions to walk away from many of their previous responsibilities in these areas. These actions by governments have also fostered uncertainty and continued complacency within the disability service sector, leading to an inheritance of outdated service models and reluctance to embrace innovation and to recognise people with disability as empowered consumers.

As a result, we have embedded a total reliance on individual funding within Tier 3 of the NDIS, leading to a critical dependence on **eligibility for and maximisation of individual support packages**, as an “all or nothing” entry point to Australian disability support, funding and service access.

The ensuing dynamic creates a strong incentive for all people with a disability to seek “eligibility for the scheme” - interpreted by most people as the attainment of access to Tier 3 - an individual package of support. Moreover, once accepted by the scheme, there is no alternative in meeting support needs other than to seek to maximise the individual package of support, and no alternative than to purchase services from the prescribed support catalogue, in the absence of other innovative and appropriate community and mainstream infrastructure and opportunities.

It is no surprise that the issue of Independent Assessments (IAs) has attracted a high degree of sector interest, because it challenges the unhealthy and unsustainable dynamic described above. However, it is well-established within Australian injury insurance scheme design, on which the NDIS was modelled, that “reasonable and necessary” entitlement, without a way to objectively and consistently define that entitlement on an individual basis, leads to inequity of resource allocation and threatens the sustainability of schemes. Typically, this leads to extensive and damaging disputes, and ultimately to scheme redesign, usually restricting benefits either to eligibility or entitlement or both - there are many examples across the 600 accumulated years of Australia and New Zealand’s 20 modern injury schemes. This dynamic has been progressively played out within the NDIS until it now has reached a point of urgent action.

The necessity of independent assessments and other scheme building blocks

Nevertheless, I believe there is still an opportunity to intervene in the NDIS structure and processes without resorting to major scheme redesign. The three pillars of technical scheme design have still never been properly implemented, and include independent assessment of support needs as one of those pillars. The most relevant recommendations of the PC with respect to independent assessments are as follows:

RECOMMENDATION 7.3

The assessment tools should be valid and reliable, relatively easy to administer and exhibit low susceptibility to gaming. The tools should be employed nationally to ensure equitable access to nationally funded support services (and allow portability of funding across state and territory borders when people move).

RECOMMENDATION 7.4

Assessments should be undertaken by trained assessors engaged by the NDIA. To promote independent outcomes, assessors should not have a longstanding connection to the person. The NDIA should continually monitor and evaluate assessors’ performance to ensure comparability of outcomes and to avoid ‘bracket creep’.

Moreover, the PC recommended these assessment tools be developed within the overall framework of the International Classification of Functioning, Disability and Health (ICF). I had previously supported the use of the ICF framework within Australia's injury insurance system³, and much of this discussion had previously been canvassed in the actuarial analysis supporting the work of the Disability Investment Group (DIG).⁴

There is now an urgent need to place these recommendations on independent assessments within the context of the three critical arms of technical scheme design essential for participant outcomes and scheme sustainability - *independent functional assessment* to support scheme eligibility and equity of resource allocation, definition of "*reasonable and necessary*" *at a package level* rather than at individual support level, and *flexibility for participants* to use this package in a way which optimises their own individual personal utility, where necessary assisted by strong and independent support coordination and support for decision-making.

I expand below on each of these components.

- *Independent functional assessment:*

The implied goal of the above recommendations is that the results of the assessment process should be consistent and reproducible, equitable across the population of participants, and produce what is established as a reasonable and necessary package of resource allocation. This is far from the case at present, whereby the result of the eligibility and resource allocation assessment processes is very much dependent on the individual member of the National Access Team or planning staff/partner organisation; in turn, this decision will be influenced by the reports and level of advocacy brought to the table by the participant and their representatives. Typically, this disadvantages less articulate people, people from lower socio-economic groups, and people from CALD or Aboriginal backgrounds. It advantages participants who are articulate or able to strongly argue a position. Moreover, increasingly it potentially extends the definition of "reasonable and necessary" in a fashion which will ultimately become unsustainable relative to the expected overall scheme investment. Again, there are many examples of this cascading inflation of support in Australian injury schemes.

As a result, the process is too often little different from the old system - still not fair in terms of access decisions or resource allocation. The goal should be that as far as possible, each person with a disability receives a fair level of support appropriate to their support needs, whether with an individual package or early intervention through so-called "Scheme access" or where possible in community supports - Tier 2 - outside of individual funding, or indeed through mainstream supports, which now need to be developed within the National Disability Strategy 2020-30.

Moreover, this "equity" at the point of resource allocation (or package determination) must take into account individual circumstances of each participant, including their personal utility and the availability and willingness of informal supports. The assessment instrument must be very clever and dynamic, and will take time to develop and legitimise. It will also require constant monitoring and refinement and engagement with the disability sector.

³ AIHW *ICF Australian Users guide Version 1.0*, Canberra 2003. At Section 10.4, p90 - the ICF and Accident Compensation in Australia <https://www.aihw.gov.au/getmedia/7d1563f4-4a77-4542-985e-5754f7439c0c/icfugv1.pdf.aspx?inline=true>

⁴ <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/disability-investment-group/pricewaterhousecoopers-national-disability-insurance-scheme-final-report> especially Sec 8.3

- *“Reasonable and necessary” at a package level:*

The discussion on independent assessment leads to the second technical requirement for optimisation of personal utility and scheme sustainability, that reasonable and necessary resource allocation occurs at a package level rather than at the level of individual components and units of support. The latter has two very different but equally important and damaging consequences:

- a. The practice of testing every support component and unit at a “reasonable and necessary” level creates an anathema for both participants and planning staff, and inevitably constrains flexible use of plan budgets, because participants are restricted in their choice and control to items and prices in the NDIS Support Catalogue. Participants are constrained in exploring market options, which in turn leads to an impediment to market development and innovation, and reinforces the intransigent and passive workforces and markets of the old system. Debate over individual items or components of support has been one of the major sources of complaint and dissatisfaction in the NDIS to date, with participants arguing strongly for more flexibility over their funding allocation.
- b. Moreover, we know from extensive modelling⁵ that the total cost of meeting all support needs of all people with disability in Australia aged less than 65 is far higher than the funding envelope of the NDIS - probably by a factor of around 250%, or in round numbers a \$50b scheme rather than \$20b. Therefore, persisting with a methodology which allows debate around the reasonable and necessary nature of each individual support not only creates an atmosphere of multiple disputes within every package, but again invites a world of very significant cost escalation, and inevitable Scheme crisis at some point. Again, such scenarios are well-known in the world of statutory insurance (for example⁶), and nearly always lead to significant legislative reform, usually some type of restriction of benefits or scheme redesign.

- *Flexibility for participants:*

Lack of flexibility as a way of controlling services and cost is a natural consequence of a system without consistent and equitable resource allocation at the package level, and has been a constant theme in participant feedback about the NDIS. There are countless examples of seemingly reasonable purchases (often very inexpensive assistive technology items) being declined by NDIA delegates because they do not comply exactly with prescribed operational guidelines, to be sometimes replaced by more expensive items which the participant has not chosen; moreover, it is likely that significant bureaucratic and therapist approval expenses have been incurred in the process, not to mention stress and delay for the affected participant.

The conundrum is that full flexibility in the Scheme at present is likely to be unaffordable, because of the previous approval of an unsustainable level of committed support⁷, itself driven by the flawed nature of the planning process. The scheme at present is “on budget” only because participants are using only around 70% of their committed support - and even this parameter is inequitable, because the “pseudo-block-funding” of Supported Independent Living (SIL) unsurprisingly has an 84% utilisation rate compared to only 61% for non-SIL participants. The following simple analysis is unlikely to contain all the nuances of the work of the Scheme actuary, but it presents the overall

⁵ Walsh J. and Dayton A. (2005) *Modelling of service levels: NSW Disability Service System*. Department of Ageing Disability and Homecare. PwC Sydney

⁶ https://www.actuaries.asn.au/Library/ACs09_Paper_Cutter.pdf

⁷ NDIS Quarterly Report, Quarter 2 2020/21, Section 5 and Appendix E

situation and growth rates, against the backdrop of a projected scheme cost of \$22b per annum including 7% administration costs:

	Quarterly NDIS report as at		
	Dec-19	Jun-20	Dec-20
Active participants in NDIS	338982	391999	432649
Committed supports in 6 months (\$m)	11091	13073	15534
Utilisation of committed supports	70%	70%	
<u>Growth over previous 6 months</u>			
Active participants in NDIS		16%	10%
Committed supports in 6 months		18%	19%

Over the six months to 31 December 2020, committed supports to participants comprised \$15.5b, or \$31b pa, and still growing; this compares to pre-NDIS national investment in disability in the order of \$7b pa (maybe \$12b in today's currency).

Therefore, in the context of scheme sustainability, full flexibility of support packages for participants is critically dependent on the active presence of the two previous technical components of independent assessment and reasonable and necessary packages. At the same time, flexibility is a critical prerequisite for optimal participant outcomes.

Paradoxically, therefore, independent assessment, reasonable and necessary packages and flexibility and choice of supports potentially frees up far greater opportunity for participants.

This fundamental interdependence of the three Scheme building-blocks to both scheme sustainability and the best opportunity for participants is something which has never been fully understood, recognised or implemented.

The importance of participant engagement, capacity building and endorsement

Notwithstanding the technical importance of these three building blocks for participant outcomes and scheme sustainability, it is understandable that many participants and service organisations within the sector are arguing strongly against this model.

The operational risk and reward inherent in the NDIS model was well understood and established in the State schemes on which the scheme was modelled, but poorly recognised in the Commonwealth government; moreover, no attempt was made by the Commonwealth to understand this risk, nor its opportunity. Accordingly, the NDIS was implemented within a welfare model of attempted control of individual service items, rather than equitable investment in individual people. The intransigent support catalogue and inappropriate information technology were consequently developed along "service payment" lines rather than "outcome opportunities".

Investment in the National Disability Strategy, Tier 2 of the NDIS, Sector Development, previous community systems and the NIIS were all sacrificed as governments moved to negotiate NDIS funding arrangements (including "in-kind" contributions) and implement the NDIS trials earlier than recommended by the PC, and without proper development of the technical requirements of the scheme described above. Ambitious phasing of State and Territory schemes into the NDIS exacerbated the lack of preparation.

Participants and service organisations have both been significant bystanders to these developments, and, for different reasons, are both suspicious of independent assessments and other potential changes.

Participants

Against this backdrop, people with a disability, whether or not that disability may warrant an individual support package in the original scheme design, have sought entry into Tier 3 of the scheme and to maximise their support package. Moreover, year on year they have argued to supplement their support with new service requests, in the absence of flexibility for their overall package and mainstream and community services.

Because of this perceived priority to maximise a support package, participants are rightly reluctant to put it at risk in a new world of independent assessment. This is regardless of the fact that the average participant not in supported accommodation is only using 60% of their package on support purchases - and unless self-managing their package, can only use that funding to purchase items from within the prescribed support catalogue.

In this context it surely makes more sense for participants to have full flexibility of their package, notwithstanding the nominal value may not be exactly what they are currently allocated.

The challenge for the NDIA is to walk with participants and their representatives along this journey of discussion in a transparent and honest fashion, for the mutual benefit. This engagement must include a more empowered Independent Advisory Council, with appropriately supported Subcommittees and Reference Groups, which must also include the more forceful advocates critical of the proposals. A way forward will only be found with active communication between these representatives and the operational and risk management arms of the NDIA.

Service organisations

For the sector of service providers, the transition from block guaranteed funding to responsive and competitive consumer driven organisations has been more difficult than they had anticipated. Moreover, the traditional workforce model has proven difficult to transition within an efficient price model, with the result that many large service providers have struggled to fully embrace the NDIS opportunity. As a result, the loudest voices from service providers have been about funding rather than about innovation and opportunities for participants.

The saviour of larger service organisations has been the old-system pseudo-block-funded model of Supported Independent Living, which was unceremoniously transferred from State and Territory systems with little input from residents and their families, and continues to absorb 40% of scheme payments on only 7% of scheme participants. Moreover, as pointed out in the NDIA SIL consultation paper⁸ and the advice of the Independent Advisory Council⁹, many participants in SIL continue to have little choice or control over their circumstances, but nevertheless have 86% of their committed supports (in excess of \$300,000 per person pa) consumed on their behalf.

Smaller therapy-based service providers have proliferated in a model which values their time highly relative to community-based capacity building models. The power imbalance enjoyed by therapists places them in an advantageous position relative to participants with disabilities, and particularly parents of children with disabilities - who have fewer alternative opportunities in the absence of

⁸ NDIA Supported Independent Living Consultation Paper, 2020

⁹ <https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5f1a5d12d0f0823a58b7a077/1598500465902/Challenges+in+housing+and+support+-+November+2019+-+paper.pdf>

investment in community and mainstream supports and capacity building infrastructure. The scheme seems at risk of reinforcing a “medical model” of early childhood intervention as presented in the Independent Advisory Council paper on this topic¹⁰.

The irony of the situation highlighted by these two examples is that the group home model and the medical model of disability, two of the systems pilloried in the *Shut Out* Report, have prospered under this imitation of the “NDIS”.

Both of these service models – SIL and therapy - will have more searching questions asked of them in terms of outcomes and value for money should the NDIS return to its original design. Understandably, their supporters are strongly resisting changes to scheme implementation.

What must happen next?

Clearly, I believe it is essential for future participant outcomes and scheme sustainability that the technical model of the NDIS be finally implemented.

However, it would be naïve and wrong to ignore the strong representation of participants in their concerns.

Given the above I believe additional actions are required from governments to support the NDIS with the ecosystem intended by the original PC report.

It is not the appropriate place to prosecute all of these actions in detail in this Submission, but in summary I believe the following plan should be initiated by governments as a matter of urgency:

- 1 The development of mainstream and community capacity must be seriously restored and embraced by all Australian governments through a strong and robust National Disability Strategy 2020-2030. The strategy needs to be tied to a transparent framework of reporting on mainstream service accessibility and failures, with a linked National Disability Data Asset tied to the NDIA data system and with access to State, Territory and Commonwealth services within a single overarching Independent governance framework.
- 2 A standalone Tier 2 of the Scheme must be recognised as a critical tool of the NDIA in managing community capacity development and service use of Scheme participants and other people with disabilities. The importance of this Tier of Scheme design was totally undervalued and exploited within the phasing stages of NDIS scheme transition, and has now been withdrawn at the critical stage of development of a post-transition ILC strategy, through its recent transfer from the NDIA to DSS, without consultation or due consideration of the likely consequences for scheme participants and sustainability. The 2011 PC report recommended \$200m pa in dedicated Tier 2 investment - this would translate to close to \$400m pa in today’s currency. This investment is essential to develop skilled and dedicated Disability Support Organisations to provide independent capacity building, support coordination and assistance in decision-making for those participants challenged in these areas to optimise the opportunity offered by their NDIS and mainstream supports.

¹⁰<https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5f741949592258189a939615/1601444208549/Promoting-best-practice-in-ECI-in-the-NDIS-March-2020.pdf>

This investment must be in addition to the LAC responsibilities of ILC community linkages, which have been sadly ignored during transition and now need to manage the gateway for participants on the cusp between Tiers 2 and 3, as well as explaining mainstream and community opportunities to all people with disabilities.

The triple planks of the NDS, LACs and DSOs provide participants, potential participants, and transferring participants with opportunities to access services outside of the individual funded support of the NDIS. This opportunity both provides outcomes of a better integrated community life, but also eases the pressure on scheme sustainability.

- 3 It is essential to legitimise the NDIA, its expert Governance Board, and its participant led Independent Advisory Council as recommended by the PC, as an Independent Statutory Corporation reporting to the Minister for the NDIS and Treasury, and accountable for its outcomes to the people of Australia through transparent reporting. As recommended by the PC, the NDIA needs a dedicated direct appropriation and sufficient risk-margin reserves and flexibility over policy levers to respond in an agile manner to emerging pressures on participant outcomes and scheme sustainability, supported by bespoke operational and ICT / digital capability. The current convoluted governance model of the NDIS has multiplied the bureaucratic complexity of the scheme, confused its objectives with welfare rather than opportunity and outcomes, and frustrated and compromised the experience of scheme participants.

The tenuous argument that attachment of the NDIA to the DSS portfolio was necessary for the Commonwealth-State/Territory negotiations of scheme transition no longer applies. Far more valuable investment of these negotiations would be to successfully stand up the National Disability Strategy 2020-30, repair the damage of the past decade, and lead the nation forward. In particular, developing and linking the NDS Reporting and Outcomes Frameworks to also encompass and make transparent the poorly recognised and reported NDIS Applied Principles and Tables of Support (APTOS) would be a major contribution. A particular “elephant in the room” requiring clarification is that people with chronic health conditions most appropriately managed in the health system (with the explicit exception of psychosocial disability) were never intended to be eligible for the NDIS within the original budget. This is a glaring flaw in the legislation, and a major financial risk to the scheme.

- 4 As discussed above there is an imperative to reinstate the three critical arms of technical Scheme design essential to achieve participant outcomes from a reasonable and necessary package rather than to maximise components of the package itself.

The implementation of these reforms needs to recognise the constructive concerns of informed critics. The more significant of these concerns raised with me from the current independent assessment pilot include:

- a. Examples of administration of the assessment tools without an overarching scheme-wide set of reference points. This is particularly the case for people with physical and mobility limitations which may not be adequately measured by the preferred instruments. Some of these disability types, for example cerebral palsy and spinal cord injury, have well understood basic diagnostic markers which can be mapped to support needs to provide high-level benchmarks. In some cases, these markers appear not to

have been adequately captured - and in their absence the assessment instruments can sometimes give questionable results;

- b. Examples of people with cognitive limitations who need independent support in decision-making and interpretation; without a trusted representative it may sometimes be difficult for these people to complete the assessment process. In some such cases the investment I have previously suggested in DSOs to provide independent capacity building and decision-making support may assist in preparing people for the assessment interview, and where necessary in helping complete the assessment; and
- c. Concerns about the logistical capacity of Australia's experienced and qualified workforce of assessors to physically complete the challenge of implementation. It is critical that the responsible arm of the NDIA adequately invest in this capability, and if necessary set implementation to an appropriate timeframe. This decision should include critical analysis of the results of the current pilot, including an impact analysis across the full spectrum of NDIS participants, and a within-pilot benchmarking of assessment outcomes by assessor and by cohort of participant, to appropriately test inter-rater reliability.

Notwithstanding these concerns, I am a strong supporter of the necessity of this plank of scheme design. Without it I fear we may be in a much weaker bargaining position in a few years. The required investment to prepare for this change needs to begin now.

- 5 The Participant Service Guarantee and Participant Vision must be affirmed and celebrated and genuinely implemented, and the Independent Advisory Council positioned within a revised Governance framework as a strong, vocal, and visible vehicle for the balancing voice of the participant and engagement with the operational management of the NDIA, and actively receiving responses on participant satisfaction as recommended by the Tune Review. There has been good work done over the past 18 months, unfortunately interrupted by COVID-19, but it is now critical that significant investment and effort brings participants and the entire cross-section of their representatives fully inside the tent.
- 6 This engagement needs to be supplemented by a strengthened NDIS Safety and Quality Commission. The tragedies of the past need to be called out and appropriate protections put in place, in collaboration with all governments through the National Disability Strategy. Moreover, there must be instituted an owner of the "Quality" dimension of the Commission. Meeting minimum standards of safety and quality compliance is a weak hurdle in the current deficit position of sector development and innovation.
- 7 This passive market development strategy has reinforced the direct relationship between service providers and governments rather than as players in a consumer directed model. There needs to be engaged market stewardship and encouragement of innovation and alternative models of support, facilitated by a workforce development strategy which recognises both the expanded opportunities for participants and the limitations of the current workforce infrastructure.

In particular this needs to embrace a revitalised Home and Living Strategy to bring options for accommodation and support into the 21st century, facilitated by flexible funding models,

innovative and flexible workforce initiatives, and assistive technology and housing investments.

- 8 The forgotten National Injury Insurance Scheme (NIIS) was intended to both ensure the smooth transition and expansion of existing State-Territory lifetime support schemes which provided multi-system support for major injury participants, but also to provide the technical models and examples from which the NDIS could learn. The total disregard of these models has both left a service delivery gap at the point of hospital discharge for many NDIS participants severely injured as a result of brain injury or spinal cord injury, and has also highlighted the lack of experience within the Commonwealth government at implementing this design of social insurance.

Closing remarks

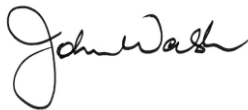
I would like to thank the Committee for the opportunity to comment on these important issues.

My comments have covered a broad range of critically important topics, mostly in a shallow fashion, and I have not attempted to specifically cover all of the 12 items of the particular Terms of Reference - I believe most of these are addressed in Chapter 7 of the 2011 PC report.

More importantly, I have taken the opportunity to place the importance of independent assessment within the framework of other shortcomings over the last decade of NDIS and other system implementation. I hope this is useful to the Committee.

I would be happy to enter into any further correspondence.

Yours sincerely,



John Walsh AM
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