



“Wounded Hearts: Life in the Depths” by Kristin Gillespie

**SUBMISSION: GENERAL ISSUES AROUND
IMPLEMENTATION & PERFORMANCE OF THE NDIS**

We thank the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for the opportunity to provide an update on the implementation and performance of the NDIS.

AT A GLANCE

VMIAC does not support the introduction of mandatory independent assessments and calls on the Commonwealth Government and NDIA to work with disabled people, families, supporters and disability organisations to redesign a fit-for-purpose assessment process.

The Victorian Mental Illness Awareness Council (VMIAC) is the peak Victorian non-government organisation for people with lived experience of mental health or emotional issues. We provide advocacy, education, consultation and information to promote the rights of people using, or wanting to use, mental health services.

VMIAC has specialist experience advocating, at an individual and systemic level, for changes to the NDIS and the National Disability Insurance Agency (NDIA). At an individual level VMIAC provides:

- Specialised information for consumers on how to apply for the NDIS
- Advice and support to gather evidence required for the NDIS
- Intensive support through the application process and planning meetings
- Advocacy support for NDIS Reviews and Appeals.

Underpinning this work is VMIAC's NDIS Critical Reference group, which provides ongoing input and advice into VMIAC service delivery and strategic advocacy.

These opportunities give VMIAC a broad understanding of the issues faced by consumers and government in implementing the original intention of the NDIS. There have been many issues with the roll out of the NDIS, particularly as it relates to psychosocial disabilities. This submission focuses on the introduction of Mandatory Independent Assessments.

MANDATORY INDEPENDENT ASSESSMENTS

There have been concerns from the disability and mental health community about a lack of consistency, fairness, transparency and equity in the NDIA's decision-making.

On August 28 2020, the Minister for the NDIS Stuart Robert announced the rollout of Independent Assessments; with the aim that this mandatory and very streamlined assessment process would be utilised to assess the eligibility of NDIS applicants, and to provide on-going assessments of participants already within the scheme.

This submission by the Victorian Mental Illness Awareness Council (VMIAC) lists some major concerns that people with a psychosocial disability have shared with us about mandatory Independent Assessments. It concludes that the Independent Assessment process is significantly flawed and needs to be abandoned immediately. This submission then highlights another growing issue regarding the systematic reassessment of the eligibility status of existing NDIS participants.

VMIAC wishes to acknowledge and thank members of the VMIAC NDIS Critical Reference Group for their input into this submission.

Major concerns around the introduction of Independent Assessments include:

- A failure of the NDIA to meaningfully consult people with disability
- The impact of Independent Assessments on NDIS participants' choice and control
- The potential harm arising from these reforms
- That Independent Assessments are not a fit-for-purpose mechanism to assess participants disabilities
- That Independent Assessments create a deterrent against accessing and engaging the NDIS, and
- These reforms reflect a broader and concerning trend of re-assessing participants without good cause

NOTHING ABOUT US WITHOUT US – THE FAILURE TO CONSULT PEOPLE WITH A DISABILITY

The NDIA has developed, and is now introducing, Independent Assessments without appropriate and transparent consultation; with people with a disability, their families, supporters and the wider disability sector, as to whether such a process will benefit and be suitable for people with a disability.

Such an approach is at odds with the Convention on the Rights of People with a Disability (CRPD), and the National Disability Strategy 2010 -2020 (2010), which seek to embed the rights of disabled people to decision making and their active participation in the design of systems that are meant to support them (see Articles 4(3) and 33, CRPD)

CHOICE AND CONTROL

Choice and control are core principles upon which the NDIS was founded. Subjecting NDIS Participants to mandatory Independent Assessments, undertaken by contracted independent assessors who may not have disability-specific expertise, is contrary to principles of choice and control. These reductionist eligibility assessments that gatekeep access to the Scheme, and introduce ongoing monitoring of participants by re-assessment, reflect a medical model of disability and institutional thinking where unknown experts hold the power to reduce the individual's level of disability to a set of numbers, without consideration given to personal circumstances, individualised needs, or life story.

THE POTENTIAL FOR HARM

There are many NDIS participants with a disability caused by injury and accident who in their long journeys through Workcover and TAC Insurance Schemes have already experienced psychosocial injury and significant trauma through being subjected to mandatory Independent Medical Assessments. (Grant, O'Donnell et al 2014).

Additionally, there are thousands of participants with a psychosocial disability who have experienced compulsory treatment and/or involuntary detention under a Mental Health Act and who know first-hand the deeply disempowering and harmful effects of being subject to institutional power. For many NDIS Participants the prospect of being forced to undertake a Mandatory Assessment in order to participate in the NDIS will be deeply triggering.

In the United Kingdom, where a similar mandatory functional assessment process was employed to reassess the eligibility status of over a million United Kingdom citizens who were receiving disability payment benefits and supports, research has been able to directly link an alarming rise in the rates of suicide and mental illness amongst disabled people to the introduction of this flawed and ill-considered policy (Barret al al, 2015).

NOT FIT FOR PURPOSE: AN INADEQUATE PROCESS OF ASSESSMENT

Under the NDIA's Independent Assessment process it appears NDIS participants will no longer be able to use assessments by people they know or trust. It is questionable efficacy to require an NDIS participant to be assessed by someone who knows nothing about them.

A recent AAT ruling *Ray v. National Disability Insurance Agency* (Sep 2020) adds weight to these doubts. The AAT ruling finding, that assessments undertaken by Ms. Ray's treating professionals were much more accurate and reliable than the assessment undertaken, over three hours by a NDIA appointed Occupational Therapist.

The NDIA, in released tender documents, stipulates a time frame (1 to 4 hours in total) for Independent Assessments carried out by an allied health practitioner. The independent assessor will have no prior knowledge of the individual in question or their disability history; and will rely instead on undertaking their assessment by asking a series of questions drawn from a suite of functional assessment screening tools to assess functional capacity.

The individual undertaking the assessment may have no knowledge or experience of the disability that they are assessing; and in fact the NDIA has said that the assessment process will be 'disability agnostic' with capacity to assess any disability accurately. But the NDIS has presented no evidence that such a limited assessment process is fit for purpose, and capable of accurately assessing or measuring a person's level of disability or disability support needs.

It is unclear how an Independent Assessment will be able to capture and measure the fluctuating and episodic nature of psychosocial disability. This is especially concerning since the Independent Assessment process that the NDIA is proposing to implement is completely untried anywhere in the world, apart from a small non-representative pilot undertaken in the Hunter Valley.

Feedback from NDIS Participants with a psychosocial disability is that they have no trust or safety in such processes. The NDIA has not provided any evidence that its proposed process is appropriate for Aboriginal and Torres Strait Islander or CALD communities, or that it will result in a fair assessment of a person with trauma or with episodic or fluctuating needs.

A DETERRENT TO NDIS PARTICIPANTS EXERCISING THEIR RIGHTS

Having to undertake a mandatory Independent Assessment each time a NDIS Participant requests a review or appeals a decision will act as a deterrent to NDIS Participants exercising their rights under the NDIS. If an NDIS Participant requests a plan review to access additional supports for a disability, there is no guarantee that the outcome of the Independent Assessment will not be used to reduce funding or supports in other areas of their plan.

There is a risk that the use of Independent Assessments could in fact be used to discredit, or discount, assessments or evidence supplied by the NDIS participant's own supports.

Where conflict or questioning arises around the validity or accuracy of an Independent Assessment, NDIS Participants will need to pay for additional assessments and evidence to challenge this process. At Internal Review, the possibility that NDIA will reverse its own decision around the validity of its own Independent Assessment process is remote. Thus, in practice the only right to appeal will be applying to the AAT for an external review of the decision/s made as a result of the assessment process. Feedback from NDIS participants with a psychosocial disability is that taking an appeal to the AAT is a highly intimidating and often insurmountable barrier for many people with a disability in exercising their rights.

A DISTURBING NEW TREND: THE REASSESSMENT OF NDIS CLIENTS ELIGIBILITY

Currently Disability Advocacy Services are hearing from growing numbers of NDIS participants (including participants with psychosocial disability, autism, fibromyalgia, chronic fatigue syndrome and a range of other conditions) who are being asked to re-prove their NDIS eligibility. This is despite that, up until recently, NDIS Participants were told that once a person qualified for support by the NDIS they would have this support for the rest of their life. Participants targeted for reassessment are being given 28 days to provide evidence that they meet NDIS eligibility criteria.

People with a psychosocial disability are a vulnerable cohort within the NDIS. In Victoria alone around 12,000 NDIS Participants with a psychosocial disability are currently listed; many of whom have very high levels of disability, who struggle to engage successfully in NDIS processes, and whose disability support needs remain unrecognized too often.

The ongoing scrutiny around the eligibility of NDIS Participants with a psychosocial disability is sowing deep apprehension for participants, about their safety and security within a scheme where their disability status is repeatedly being questioned. Many participants are experiencing this as a form of abuse and gaslighting.

RECOMMENDATIONS

Mandatory Independent Assessment Process

The NDIA's proposed Independent Assessment process is conceptually flawed, unfit for purpose and needs to be scrapped and redesigned. It needs full collaboration and consultation with disabled people, their families, supporters and the disability sector, to ensure that confidence and safety in how the NDIS operates is restored.

Recommendation 1: Collaborate to redesign the assessment process

The NDIA needs to draw on the skills, expertise, and best practice approaches, of Occupational Therapists and other Allied Health Practitioners, who are already providing assessments to NDIS Participants. By working together collaboratively there is no reason why a high quality, world-leading, safe and equitable assessment process can't be agreed upon which can service the needs of NDIS Participants and the NDIA.

The NDIA must fulfill its commitment to disabled people: by making funding for assessments readily available to all people making applications to the NDIS and continue to provide funding for ongoing assessments when required for NDIS participants. Under Section 6 of the NDIS Act the provision of such support is already stated and there is no reason why inequity should exist for any member of the community under a properly functioning NDIS.

In the event that a decision is made to continue to push ahead with mandatory Independent Assessments: a process of independent monitoring, oversight and review is put in place with the involvement of consumer and disability organisations. To ensure that any harms and impacts on NDIS participants, caused by Independent Assessments, can be quickly identified and addressed.

Recommendation 2: Reassessment of NDIS participant eligibility

VMIAC recommends that the targeting of NDIS Participants by disability type is ceased immediately. And that special support is put into place to ensure that all NDIS Participants are given the funds and the opportunity to undertake assessments or retrieve or locate evidence, when required; that can provide greater clarity and insight into the impact and level of their disability.

“The MH NDIS Experience” By Kristin Gillespie

I lay my plight out before you
I feel vulnerable and exposed
I don't like asking for help but I must
I wait with hope...

You speak

Your judgement yawns wide and cavernous
My needs vanish from sight, swallowed whole
Drowned in the clamour of misunderstanding

I try to walk on anyway
Feeling angry and despairing

I lay my plight out before you
I feel vulnerable and exposed
I don't like asking for help but I must
I wait with hope and trepidation...

You speak

Your forms do not have boxes which fit me
My needs are not quite right
Asking too little / too much, being too sick / too well

I try to walk on anyway
Feeling somehow / anyhow a misfit

I lay my plight out before you
I feel vulnerable and exposed
I don't like asking for help but I must
I wait with little hope and much trepidation...

You speak

Your platitudes rain down from oblivion
My needs unheard cannot be met
Being offered excruciatingly unhelpful help

I try to walk on anyway
Feeling completely unseen

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I lay my plight out before you
I am vulnerable and exposed
I don't like asking for help but I must
I wait with trepidation...

You speak

Your disingenuous responses whitewash reality

My needs completely denied
Being blamed and gaslighted for my trauma
I am unable to walk, only crawl on
Feeling shattered and shamed

I lay my plight out before you
I am vulnerable and exposed
I don't like asking for help but I must
I wait in complete despair...

You speak

Your offer of imperfect help says you “get it”

My needs are somewhat met
Offered real help after so much searching
I can walk on with some dignity
Feeling relief and gratitude

Maybe I can manage, next time
Maybe I can help someone else, next time
Maybe if you hadn't helped there would be ... no next time

Kristin Gillespie © February 2018
(variation on The Client's Experience © February 2012)

REFERENCES

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FURTHER READING

UN General Assembly, Convention on the Rights of Persons with Disabilities, 13 December 2006, A/RES/61/106, Annex I, available at

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