



p. 07 3004 6926 e. mifa@mifa.org.au w. www.mifa.org.au
MINetworks 1800 985 944 www.minetworks.org.au

Submission to the Australian National Audit Office:

Audit of Decision-making controls for sustainability – National
Disability Insurance Scheme access

Patron : His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd)
President: Mick Reid

Mental Illness Fellowship of Australia (MIFA) is a federation of long-standing member organisations, delivering specialist services for individuals living with mental illness and their friends and families. MIFA members operate out of over 180 'front doors' in metropolitan and regional areas, and support 30,000 people living with mental illness and their carers each year. Our membership has a strong focus on building community, valuing peer support and lived experience, and supporting recovery. We have substantial experience delivering specialist, place-based, community-building programs to those experiencing mental illness, and over 50% of our workforce has a lived experience as a consumer or carer; as such, we feel we are well placed to assist the Australian National Audit Office in their audit on the access decisions in the National Disability Insurance Scheme (NDIS), and we welcome the opportunity to provide our input.

There are significant barriers for people with a psychosocial disability attempting to apply to the NDIS. Psychosocial disability had the lowest eligibility rate of all disability groups for applications to the NDIS (apart from access determinations in 'Other' or 'Missing' categories), with only 71.3% of access determinations resulting in an individual support plan¹. There are further participants in current MIFA member programs who are choosing not to apply at all. Although the audit may seek to understand the procedures in place to support appropriate access decision-making on the part of NDIA staff, MIFA has chosen to define access broadly to include barriers caused by lack of information provision and additional supports required to truly facilitate access to the NDIS for those with psychosocial disability. These barriers include:

- the lack of clarity about the eligibility criteria for those with psychosocial disability;
- the lack of awareness among health professionals around how to define functional impairments;
- the lack of capacity for service providers to reach out to participants who may be hesitant about engaging with the NDIS;
- the need for extensive practical and emotional support throughout the process of applying and planning (which can be experienced as distressing and invasive); and
- the lack of training and sensitivity among NDIA staff.

These access issues could be addressed through a number of initiatives, including:

- clearer eligibility criteria to ensure there is no ambiguity about NDIS eligibility in the context of psychosocial disability;
- additional resources to train health professionals in the community to support their documentation processes, as well as improvement to administrative systems to streamline evidence gathering from health professionals, medical services and the public health system;
- assertive outreach and 'pre-planning' support services for people with psychosocial disability, that sit outside of planning or access determination services; and
- training to NDIA staff and NDIA agents to ensure assessment processes are supportive of those with psychosocial disability.

¹ National Disability Insurance Agency (NDIA) (2017). COAG Disability Reform Council Quarterly Report Q2 2016-17

Lack of clear eligibility for psychosocial disability

Eligibility for the NDIS for those with psychosocial disability is an ongoing area of debate amongst mental health policy makers and providers. Mental health service providers strongly advocated to include mental health services in the NDIS, in acknowledgement of the significant functional impact and debilitation caused by severe and persistent mental illness. However, eligibility criteria for the NDIS needs to be urgently clarified. This issue has been outstanding for several years, and has been repeatedly raised by Mental Health Australia, Community Mental Health Australia, the National Mental Health Commission (NMHC)² and MIFA, among others. Clarifying access for individual NDIS packages is particularly relevant for planning how the rest of the system will provide for the gaps: as former National CEO of MIFA, Mr David Meldrum stated “Until we are clear about who is in, we cannot plan for those who will be out.”

The original Productivity Commission (PC) estimates indicated 12% of those with a severe mental illness should be ‘in scope’, or 57,000 people³ – now updated to 65,000 people due to population growth. The original PC report indicated those anticipated to be included in the scheme were individuals who:

- have a severe and enduring mental illness (usually psychosis)
- have significant impairments in social, personal and occupational functioning that require intensive, ongoing support
- require extensive health and community supports to maintain their lives outside of institutional care.

This target group definition is in addition to the age (under 65), residency and permanency requirements. This same target group was characterised by the Australian Government Actuary (AGA) review of NDIS Costings⁴ as those having “complex needs requiring co-ordinated services from multiple agencies” (p14), while the National Mental Health Commission’s Review of Services 2014⁵ characterised this group as “people with severe and persistent mental illness with complex multiagency needs – requiring significant clinical care and day-to-day support” (p46) and “very high level of need”.

These definitions provide inadequate operational clarity around how those with ‘severe, persistent and complex needs’ needs might be distinguished from the much larger cohort of people with severe mental illness who also have significant impairments in functioning, and require extensive community support. The National Disability Insurance Agency (NDIA) has not provided specific guidelines to delineate this population with ‘severe, persistent and complex’ needs, and there is little transparency to those applying how decisions about access are being made in the context of psychosocial disability. The use of broad eligibility criteria presents the risk that access decisions are being made in an inconsistent or arbitrary way.

² Recommendation 3 in National Mental Health Commission (NMHC) (2014). *Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services*.

³ Productivity Commission (PC) (2011). *Disability Care and Support: Productivity Commission Inquiry Report*, 54(2), Canberra.

⁴ Australia Government Actuary (AGA) (2012). *NDIS Costings – Review by the Australian Government Actuary*.

⁵ NMHC (2014). *Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services*.

Currently, NDIA access decision-makers are relying heavily on the issue of permanency - requiring documentation both to evidence that a diagnosis exists for an impairment that is, or likely to be permanent (Section 24(1)(b)⁶), and that the person is likely to require support permanently (“for the person’s lifetime”) (Section 24(1) (e)). The requirement for permanent impairment is problematic in the context of psychosocial disability. There is some debate about whether the requirement for permanency of disability or diagnoses should include an exemption for those with psychosocial disability. The provision for early intervention, and the allowance that the level of impairment may vary, goes some way to opening eligibility for those with psychosocial disability, requiring only that supports are needed now to avoid lifetime support being necessary; however, the impairment itself still needs to be, or be likely to be permanent.

Constructs of permanency can be at odds with a recovery framework. In one case study, a participant was granted access based on their health professional’s documentation; however, during the planning phase, the participant refused to characterise their experience of mental ill health as permanent and was consequently given a plan with almost no supports. The somewhat fraught definitional alignment between discourses of physical disability and those of psychosocial disability, as well as misunderstanding from health professionals and NDIA assessors about the course and nature of psychosocial disability, hinders access to the NDIS for those with psychosocial disability. There are opportunities for alignment between the NDIS and psychosocial recovery, as has been explored elsewhere⁷, and MIFA acknowledges the internal and external work that the NDIA has done in an attempt to reconcile these differences and support access processes⁸. However, in practice, these definitional issues continue to result in misunderstanding from health professionals about what is required in supporting documentation; inappropriate access determination refusals; and resistance to engage with the NDIS from consumers.

In the absence of clearer guidelines, access decision-makers may rely on stigma-informed judgments about which psychiatric diagnoses are likely to impact on functionality or require complex care. Psychiatric diagnoses alone should never drive access decisions, as these do not necessarily indicate the severity, persistence, permanency or level of need for support. Those with mental illnesses characterised in the popular discourse as ‘malingering’⁹, ‘not a real medical illness’¹⁰ or not commonly considered to be permanent or severe may be discriminated against. There is already evidence of diagnoses-driven decision-making both anecdotally from our member service providers (based on feedback from NDIA assessors), and in trial site

⁶ *National Disability Insurance Act 2013* (Cth) No. 20, 2013 (NDIS Act)

⁷ O’Halloran, P. About Psychosocial Disability and the NDIS, Introduction to the Concept of Holistic Psychosocial Disability Support. <https://www.ndis.gov.au/html/sites/default/files/O'Halloran%20paper.pdf>

⁸ Including the pending Best Practice Guide for Access to the NDIS, public factsheet “Psychosocial disability, recovery and the NDIS”, and guide “Completing the access process for the NDIS: Tips for Communicating about Psychosocial Disability”.

⁹ Ross, C., and Goldner, E. (2009). ‘Stigma, negative attitudes and discrimination towards mental illness within the nursing profession: a review of the literature.’ *Journal of Psychiatric and Mental Health Nursing*, 16, pp 558–567.

¹⁰ Reavley, N., and Jorm, A. (2012). The 2011 National Survey of Mental Health Literacy and Stigma Summary report. http://pmhg.unimelb.edu.au/research_settings/general_community?a=636501

evaluations which showed that those with PTSD, depression & mood disorders are more likely to be declined a package.¹¹ This is particularly concerning as people with mood disorders often make up the largest percentage of those in programs set for transition into the NDIS.¹²

It is imperative that eligibility for those with psychosocial disability is more clearly defined, both to ensure that the NDIS is targeted at those most in need for whom it was intended, and to avoid the possibility of budget overshoots. Mental Health Australia's technical report by David McGrath¹³ analysed the National Mental Health Service Planning Framework (NMHSPF) modelling (under development), and revealed a population of 502,000 adults with severe mental illness in Australia, of whom approximately 290,000 will require some form of NDIS-like community support, defined as "non-clinical community based services designed to assist those with a mental illness to participate in their communities and have meaningful and contributing lives." This figure is more than five times the number of people estimated by the PC in 2011.

Guidance for evidence-gathering

There are no clear psychiatric diagnosis-informed prognoses that can reliably predict whether a person will be permanently impaired by a mental health condition, or require permanent support. It is difficult, therefore, for health professionals to give evidence to that effect, particularly health professionals who do not subscribe to an organic or medical model of mental illness. Health professionals are often unwilling to state that an impairment is or is likely to be permanent, both because this may be medically impossible to predict, but also because it is at odds with a recovery framework in which it is hoped that symptoms can be effectively managed to the point that the impairment may cease to exist absolutely (rather than simply varying to a lower level of intensity). It is also unclear how applicants can best prove that supports for their condition are not most appropriately funded by "general systems of service delivery or support services" (Section 25 (3)), given both clinical and psychosocial supports may be required indefinitely, and there is confusion even within the sector about how some supports or services can be delineated as either psychosocial *or* clinical; psychosocial-style interventions may have clinical outcomes, and/or be provided by clinicians.

In MIFA members' experience, health professionals often require 'coaching' to understand psychosocial disability and provide documentation of the person's condition that will be acceptable to the NDIA and its agents. This should not be incorrectly construed as an effort to fit those in to the NDIS who may ordinarily be ineligible, as advocacy around documentation has also been required for people with high needs, complex issues and severe and persistent mental illness (who make up the majority of MIFA members' participants). Intensive

¹¹ 15% of people with mood disorders had their application declined, see p10 in Hunter Primary Care and 360 Health and Community (2015). *Partners in Recovery and NDIS Interface: A Data Report from the Hunter and Perth Hills Trial Sites*, <https://hunterpir.com.au/wp-content/uploads/2015/12/PIR-NDIS-Interface.pdf>

¹² 27.8% of NSW PIR clients had mood disorders: p20, Amos, P. (2015). *Persistent Mental Illness And Complex Needs A Project Of New South Wales Partners In Recovery Organisations*

¹³ Mental Health Australia's Submission 1 - Attachment 1: McGrath, D. (2016). *The Implementation and operation of the Psychiatric Disability Elements of the National Disability Insurance Scheme: A Recommended Set of Approaches*

preparation, vetting of documentation and coaching to supporting personnel such as GPs and Psychiatrists, as well as the individual and their carers, is required to help frame their responses in ways acceptable to the NDIA. The NDIA needs clearer external guidance to applicants, their carers and in particular to health professionals. There is also a need for training to health professionals and other mainstream services on how to support and provide evidence for people to access the NDIS.

In the context of psychosocial disability, functional impact assessments may be the best way to evidence a need for an NDIS package. Cost-free access to health professionals trained to translate symptoms into functional impacts, using tools well-adapted to assess functioning in the context of psychosocial disability, should be embedded in the access process for the NDIA. Some MIFA member organisations have added (unfunded) occupational therapists to their staff to support this process.

Finding those hard-to-reach

In addition to barriers arising from confusion around eligibility, and lack of clear guidelines for evidence provision, service providers report a number of psychosocial-specific barriers to NDIS access due to the impact of psychosocial disability itself. Research indicates that around 54% of people with mental ill-health do not seek help¹⁴. There is a large cohort of ‘hard-to-reach’ people who may not be connected with services at all, and require assertive outreach supports to facilitate their access to the NDIS. People with psychosocial disability struggle with to access services due to internalised stigma, ambivalence about desire to access support, and the need for flexibility of services. The particular burden of stigma, shame and fear of disclosure in the context of mental illness may impact on an individual’s desire to go through the invasive assessment process required in the NDIS. The inability to access NDIS supports without committing to the full process creates a barrier for those who may not recognise their support needs, or be at a contemplative stage¹⁵ of understanding their need for support and wanting to explore options only. This presents a significant issue for service system planning and policy; with over half of the target population not presenting to services, it follows that a reasonable percentage of resources must be dedicated to supporting help-seeking behaviour and reducing barriers for access.

There is a clear and urgent need for specialist support to ensure those who are disconnected or struggling to connect with the NDIS are able to gain access. These needs can be met through the provision of assertive outreach support and pre-planning services. Partners in Recovery (PIR), a program set for transition into the NDIS, incorporates a strong assertive outreach framework, which meets participants where they are at and works through resistance to help-seeking – including resistance to NDIS applications. Experience has shown that public campaigns and information provision are inadequate to reach those most disenfranchised and disconnected from supports. One service provider described a case study where an outreach

¹⁴ Whiteford HA, Buckingham WJ, Harris MG, et al. Estimating treatment rates for mental disorders in Australia. *Australian Health Review* 2014; 38(1): 80-5.

¹⁵ For information about the Stages of Change model of intervention, see Queensland Health (2007). *Stages of Behaviour Change*, https://www.health.qld.gov.au/_data/assets/pdf_file/0026/425960/33331.pdf

worker spent several months attending a participant's home regularly and simply talking and being present, before the person experiencing mental ill health finally gained trust in the worker and the process enough to seek other supports and treatment.

The 2015 review of NSW PIR services indicated assertive outreach strategies were successfully able to connect with excluded cohorts, including people experiencing homelessness and Aboriginal and Torres Strait Islander people¹⁶. Assertive outreach involves devoting time and resources to actively seeking out people in the community (e.g. rough sleepers), and building trust and engagement with people prior to their entering formal service. It also involves having resources available for consumers to connect with services in an unplanned way, for example through connecting to support workers via telephone, having face to face drop-in centres available, and after hours supports. Assertive outreach practices need to be integrated into the NDIA access process; alternatively, existing services with the visibility, diagnostic-specific expertise, and pre-existing connections with the community should be funded to support people to access the NDIS.

The need for pre-planning support & mental health sensitive practices

In addition to the need to support people to consider accessing the NDIS, those with psychosocial disability who are applying require significant support throughout the process. MIFA members report that both the design and implementation of the access determination process has in some cases resulted in an exacerbation of illness (including reports of hospitalisations resulting directly from NDIS access and planning processes). People with psychosocial disability require pre-planning support from support people who have deep understanding of the system in order to navigate these processes safely. The process of information gathering, contacting health professionals, and collating information in order to complete the access request is a task some people with psychosocial disability find impossible to manage on their own. Having to re-contact a range of people to gather evidence on the history of illness, as well as the experience of being 'interviewed' and assessed, can be experienced as extremely invasive and in some cases, triggering. This has been aggravated by experiences of insensitivity and a lack of understanding about mental health from NDIA staff. Symptoms related to psychosocial disability itself can present barriers to access, such that those with anxiety and trauma may require significant support to prepare and attend assessment appointments in which they are exposed to strangers and may feel threatened, judged or vulnerable.

MIFA member experience is that participants who are supported by specialists to gather evidence, complete their access request form, and attend planning sessions are more likely to be found eligible and receive much higher packages than those acting alone – even where the impairments and support needs are equal. This suggests a gap in the information or resources available to applicants, such that participants require additional support from community

¹⁶ Amos, P. (2015). Creating Better System Responses For People With Severe And Persistent Mental Illness And Complex Needs A Project Of New South Wales Partners In Recovery Organisations

services and carers to understand what the NDIA needs and navigate its bureaucratic processes. This is a failing in the way the NDIA is supporting applicants with psychosocial disability. While it is clearly important to ensure those applying are genuinely in need of the benefits provided under the NDIS, the application process places significant pressure on those applying, and their support team. Currently specialist service providers are drawing on other resources (whether loss-leading or as part of support under current programs due for transition such as Partners in Recovery or PHaMs) to facilitate access for people into the NDIS. The level of NDIS “success” in granting access, which often relies on this behind-the-scenes high level support, and also requires regular use the appeals process, is not sustainable.

Practices by the NDIA or its agents such as calling transitioning participants without fore-warning, conducting telephone interviews, and/or failing to communicate regularly with applicants has exacerbated participants’ anxiety and caused considerable distress. The pressure to transition from previous programs and the lack of other psychosocial supports has resulted in significant demand on assessment processes, and consequently, significant delays in the process; if a participant has questions about the process, they are required to call the 1800 number, which frequently has a wait time in excess of several hours, and there is a long wait time of up to several months between access being granted and planning meetings being set. Despite the current burden on administrative processes at the NDIA, communication in particular with participants with a mental health issue should be conducted in a clear, timely manner, and where possible, face to face, so as to not further exacerbate mental health difficulties.

The practice of rejecting an access request outright, rather than requesting that applicants provide further evidence to meet the gaps, or following up with health professionals on the evidence submitted, discourages vulnerable people from appealing, and discourages their peers from applying. Emerging case stories indicate that people experiencing regular and extreme symptoms which would clearly impact on their daily living have not been considered eligible by NDIA access decision-makers; refusals articulate the sections of the Act that are not met, but not in what way they are not met nor in what way the evidence provided could better show eligibility. There is concern that decision-makers, who may be at a level APS3 or APS4, may not have any mental health expertise or clinical knowledge required to understand someone’s experience of mental ill-health. This suggests there may be a need for specialist mental health assessors to ensure decision-making is consistent and contact with participants is respectful.

s55 data

MIFA also notes there have been significant access issues associated with the s55 process. These include incorrect data transmission from State and Territory data. For example in North Queensland, where contact information provided by Queensland Health was not correct, many clients are still awaiting contact from the NDIA despite roll out occurring in 2016. In cases where the primary diagnosis was not correctly entered in Government systems, participants have been incorrectly deemed ineligible or had planning decisions based on their secondary or tertiary diagnoses. There have been additional significant concerns from MIFA members around confidentiality and the process of contacting prospective NDIS participants. These include

concerns that contacts to participants has not been managed in a sensitive manner, and the experience of having data transferred has been experienced as a breach of trust. These issues are more fully outlined in MIFA member One Door Mental Health’s submission to this audit.

MIFA thanks the Australian National Audit Office for the opportunity to provide input into the audit.

Contact

Tony Stevenson – CEO – MIFA



Written by

Rohani Mitchell – Policy & Strategy Advisor – MIFA

Tony Stevenson – National Chief Executive Officer – MIFA

Disclaimer

This submission represents the position of MIFA. The views of MIFA members may vary.