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Submission to the Productivity
Commission:
Review of National Insurance Disability
Scheme (NDIS) Costs

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 Productivity Commission in their Review of National Disability Insurance Scheme (NDIS) costs and we welcome the opportunity to provide our input.

MIFA wishes to make the following preliminary comments. We welcome the specified focus of the review on structural (systemic) issues that affect the sustainability of the Scheme over the longer term. It can indeed be challenging to separate out short-term, 'teething issues', from issues that are imbedded in the design of the Scheme itself. However, we note that we have relayed our experience of some transitional issues because we see them as related to the Scheme design and to its systemic implementation. These issues must be rectified in a systemic way order to ensure the Scheme reaches those for whom it was intended.

Eligibility for the NDIS

- *To what extent have the differences in the eligibility criteria in the NDIS and what was proposed by the Productivity Commission affected participant numbers and/or costs in the NDIS?*
- *Are there other aspects of the eligibility criteria of the NDIS that are affecting participation in the scheme (to a greater or lesser extent than what was expected)? If so, what changes could be made to improve the eligibility criteria?*
- *To what extent is the speed of the NDIS rollout affecting eligibility assessment processes?*
- *Why are more participants entering the scheme from the trial sites than expected? Why are lower than expected participants exiting the scheme?*
- *Is there likely to be a need for a provider of last resort? If so, should it be the NDIA? How would this work?*

Lack of clear eligibility and the risk of cost over-runs

The eligibility criteria proposed in the original Productivity Commission lacked clarity in the first instance, and this lack of clarity has the potential to threaten not only the Scheme's sustainability, but also its ability to reach the cohort for whom it was originally intended. The criteria do not provide enough specificity to adequately delineate those who should be in the Scheme, versus those who should be supported in a different way. The eligibility criteria need to be urgently clarified. This issue has been outstanding for several years, and has been repeatedly raised by Mental Health Australia, CMHA, the National Mental Health Commission

(NMHC)¹ 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 retired 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 people² – now updated to 65,000 people due to population growth. However, the NDIA has not provided specific guidelines to delineate this population with ‘severe, persistent and complex’ psychiatric needs. The PC indicates 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.³

This target group definition is in addition to the age (under 65), residency and permanency requirements.

However, this definition provides inadequate clarity around how those with ‘severe, persistent and complex’ needs might be distinguished from the much larger cohort of people with severe and enduring mental illness, who also have significant impairments in functioning, and require community support.

The 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). The AGA suggested that the NDIS may not be restricted to those with high level needs, but rather that the definition turned more around the permanency and significance of the disability. They also noted that using the type of support required to distinguish between groups is not sufficient to provide more specificity, as the kinds of needs required by those at different levels of psychiatric disability are often similar, although the degree may vary. The estimates included 424,000 people with mental illness requiring some kind of community support, not covered by the NDIS.

¹ Recommendation 3 in National Mental Health Commission (NMHC) (2014). Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services.

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

³ p754-p755, 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.

The AGA report presented the stratification of the population as follows:

Description	Care Needs	NDIS coverage
Episodic mental illness (est. 321,000 people)	Clinical services both during episodes of illness and to maintain remission between episodes Disability support services may occasionally be required, particularly during a lengthy episode of illness	Not included Not included
Severe and persistent mental illness but can manage own access to support systems (est. 103,000 people)	Clinical services Social inclusion programs	Not included Not included
Complex needs requiring coordinated services from multiple agencies (est. 56,000)	One on one support from a carer (paid) Supported accommodation, where appropriate Social inclusion programs Clinical services	Included Included Included Not included

AGA (2012)⁵

The NMHC Review of Services 2014⁶ presented a similar population estimate for the complex needs group (taking in population growth) at 65,000. They 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”. Their breakdown of psychiatric disability outside of the highest needs group had higher estimates than the PC (including around 625,000 people requiring support outside of the highest needs group).

High-Very High Needs <ul style="list-style-type: none"> Personal and flexible packages of comprehensive health and social care (including housing, income and employment support) Specialist mental health and physical health treatments Co-ordinated care - One system, one care plan, one e-health records 	Very high level of need	0.15% (65,000 people) Severe and persistent illness with complex multi-agency needs Require significant clinical care and day-to-day support
	High level of need for support	1% (210,000 people) Severe and persistent Chronic with major limitations to function (ie very disabling) and without remission over a long period

⁵ p14, AGA (2012). NDIS Costings – Review by the Australian Government Actuary.

⁶ NHMC (2014). Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services.

		2% (415,000 people) Severe episodic Severely episodic with periods of remission
Low-Moderate Needs <ul style="list-style-type: none"> • Targeted and integrated clinical and social support • Housing, income, psychosocial supports • Self-directed low intensity therapies • Early interventions • Maintain connections with families, friends, culture and community 	Moderate level of need for support	5.5% (1 million people) Moderate
	Low level of need for support	11% (2 million people) Mild 45% (7.3 million people) Will experience a mental disorder sometime in their lifetime
For the Population <ul style="list-style-type: none"> • Investment in prevention and early intervention • Foster healthy communities and encourage self help • Foster mental resilience (families, schools) 	Need for wellbeing and resilience promotion	Majority (22.68 million people) Need for wellbeing and resilience promotion

NHMC (2014)⁷

Further population profiling is provided in Mental Health Australia’s technical report by David McGrath⁸. His analysis of the National Mental Health Service Planning Framework (NMHSPF) modelling (under development) 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 5 times the number of people estimated by the PC in 2011. He also identified at least 153,600 carers – or more, depending on how many carers each mental health consumer has – who require some form of support.

Based on the above three sources, there is some agreement that a sub-set of those with mental illness exist who have high-level, complex needs and require significant, potentially daily support, and that based on today’s population has a prevalence of around 64,000 – 65,000

⁷ p46, NHMC (2014). Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services.

⁸ McGrath, D. (2016). The Implementation and operation of the Psychiatric Disability Elements of the National Disability Insurance Scheme: A Recommended Set of Approaches, available at: <http://www.aph.gov.au/DocumentStore.ashx?id=2102830b-fade-440f-b4e1-c498d1a70490&subId=461257>

people. There is less agreement about how many people sit outside of the scheme but require 'community' or psychosocial support, with estimates ranging from 225,000⁹, 424,000¹⁰ and up to 625,000¹¹.

Departmental advice to service providers has been to encourage all those with community support needs and/or in existing psychosocial programs to apply for individual plans under the NDIS, and leave it to the NDIA to manage access demand. The Department highlights the experience of service providers who are transitioning up to 80-95% of PHaMs participants into the NDIS, as evidence of the broad eligibility of that cohort. Service providers are likely to push for maximum transitioning of clients in an effort to ensure service coverage for their existing clients, and due to the financial incentive for their own organisations in the absence of block funding for any other psychosocial support programs. Because the rest of the mental health community support system has been absorbed to fund the NDIS, there is a sense that the only choice is the NDIS or nothing.

MIFA is concerned that this approach may result in skewed use of resources, false expectations, and disappointment. As the scheme rolls out, the high transition rate of existing program participants will blow out the target for the scheme. As existing programs which have taken pressure off the NDIS are scaled back, the unmet demand for psychosocial services will increase. There is a clear risk of overspend if the NDIA chooses to expand the eligibility ad hoc to include all those with psychosocial disability. This could account for higher than expected numbers continuing to enter the Scheme in trial areas.

The most concerning aspect, however, is that the push to include all those with a psychosocial disability could perversely end up excluding those with the greatest need. There are many people requiring community support and/or in existing programs who do not have the "very high complex" needs that the NDIS individual packages were intended to address. Those with the most complex needs, who are hard to reach and excluded from any services, will not be supported because the resources are directed to those more easily transitioned, and the targets will be filled with lower needs clients. The low cost margins, significant workforce adjustment issues, and challenging nature of the highest needs clients does not incentivise targeting those most in need. The Scheme runs the risk of requiring a 'provider of last resort' where service providers choose not to enter or stay in the market. As one MIFA member noted,

"Who is going to look after someone with a personality disorder, diabetes, and experiencing homelessness, when you can get the same amount for looking after someone who is much easier, for want of a better word? We have always considered ourselves to be a provider of last resort, because we take clients that others won't, and that are too hard to get in anywhere. This is difficult to do under the NDIS structure."

⁹ Based on McGrath's analysis (ibid) of population with community support needs (290,000) minus the NDIS target group in today's estimates (65,000).

¹⁰ p14, AGA (2012). NDIS Costings – Review by the Australian Government Actuary.

¹¹ P46, NHMC (2014). Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services.

Unless every effort is made to identify every person with the most complex needs and highest level of disability, and provide them with a comprehensive, individualised package of support, we will once again fail to realise the unfinished business of institutional reform which began some 30 years ago. In addition to ensuring the scheme is targeted at those for whom it was intended, the rest of the service system needs to be adequately funded, to avoid over-burdening the NDIS. As noted later in this submission, the transition of funding needs to be carefully managed to ensure specialised community supports remain for those outside the scheme; the flow of funding should be publically tracked and regularly reviewed.

The use of broad eligibility criteria also presents a risk that access decisions will be made in an inconsistent or arbitrary way. 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. Those with mental illnesses characterised in the popular discourse as ‘malingering’¹², ‘not a real medical illness’¹³ or not commonly considered to be permanent or severe may be discriminated against. There is already evidence of diagnoses-related decision-making both anecdotally from our member service providers, and in trial site evaluations which showed that those with PTSD, depression & mood disorders are more likely to be declined a package.¹⁴ This is particularly concerning as people with mood disorders often make up the largest percentage of those in programs set for transition.¹⁵ A person’s diagnosis does not necessarily indicate the severity, persistence, permanency or level of need for support.

MIFA, Mental Health Australia and Community Mental Health Australia (CMHA) agree on the need for a more specific definition along the following lines:

Complex, severe, ongoing disabilities resulting from severe and persistent mental illness (with recent diagnostic evidence). Additional evidence might be several of—

- *frequent hospitalisation for mental illness, or current or recent history of being on the caseload of public mental health services*¹⁶
- *minimal employment in recent years*
- *poor physical health*
- *insecure housing*
- *extreme social isolation*
- *insecure/non-existent informal carer support*¹⁷

¹² 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.

¹³ 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

¹⁴ 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>

¹⁵ 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*

¹⁶ Noting that evidence from trial sites indicated that many with psychosocial disability were not previously known to mental health services, and indeed may actively avoid the public mental health system

¹⁷ Noting that the presence of carer should not *prohibit* access to the NDIS

Such a definition would enable greater specificity to target the intensive individual plans to those with greatest need, and ensure the funding is aimed at the cohort for which it was originally intended.

Access issues

There is significant unmet demand on the NDIS individual support program (due mostly to the lack of funding for other psychosocial supports), and significant barriers for people with a psychosocial disability attempting to apply. These access issues are impacting on participation in the Scheme. 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 plan¹⁸. 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 access.

Specific barriers for people with psychosocial disability

Service providers report a number of psychosocial-specific barriers to NDIS access. While it is clearly important to ensure those applying are genuinely in need of the benefits provided under the NDIS, the stringent application places significant pressure on those applying, and their support team. 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 a trained advocate in order to navigate these processes safely.

The characterisation of eligibility for NDIS represents a barrier in itself. Constructs of permanency and persistence can be at odds with a recovery framework. 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 elsewhere¹⁹, and MIFA acknowledges the internal and external work that the NDIA has done in an attempt to reconcile these differences and support access processes²⁰. However, in practice, these definitional issues continue to result in misunderstanding from health professionals, inappropriate access determination refusals, and resistance to engage with the NDIS from consumers.

¹⁸ National Disability Insurance Agency (NDIA) (2017). COAG Disability Reform Council Quarterly Report Q2 2016-17

¹⁹ 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>

²⁰ Including the Operational Access Review for Psychosocial Disability, public factsheet "Psychosocial disability, recovery and the NDIS", and guide "Completing the access process for the NDIS: Tips for Communicating about Psychosocial Disability".

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).

The process of information gathering, contacting health professionals, and collating information 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. 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. 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.

People with psychosocial disability also struggle with accessing the NDIS due to stigma, ambivalence about desire to access support, and the need for flexibility of services. Research indicates that around 54% of people with mental ill-health do not seek help²¹. 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 stage²² 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.

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;

²¹ Whiteford HA, Buckingham WJ, Harris MG, et al. Estimating treatment rates for mental disorders in Australia. *Australian Health Review* 2014; 38(1): 80-5.

²² 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

- training to NDIA staff and NDIA agents to ensure assessment processes are supportive of those with psychosocial disability; and
- assertive outreach and ‘pre-planning’ support services for people with psychosocial disability, that sit outside of planning or access determination services.

The need for pre-planning and assertive outreach supports

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 and pre-planning services. As previously noted, the NDIS was aimed at those with the most complex, severe and persistent mental illness – a cohort of people who will also be impacted the most by the barriers to access described above. The Scheme needs to ensure there is incentive to support those most in need.

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. Programs such as PHaMs have no lag-time for support, and much less restrictive eligibility criteria, meaning someone can immediately start working with a peer support worker or other professional, rather than needing to be assessed and then be allocated support resources.

Partners in Recovery (PIR) 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 is inadequate to reach those most disenfranchised and disconnected from supports. One service provider described a case study where an outreach 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 people²³. 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. These services need to be integrated with NDIS service provision, so that participants feel safe connecting to a known provider (rather than connecting with a completely different service).

MIFA has strong reservations about the ability of Local Area Co-ordinators (LACs) to fill this gap in assertive outreach and pre-planning needs in the future, given their already large area of responsibility (both planning and networking), and their lack of specialist psychosocial expertise. Assertive outreach and pre-planning supports should be provided by services who

²³ 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

have visibility, diagnostic-specific expertise, and pre-existing connections with the community they serve. Best practice also supports the concept of continuity of care²⁴, such that an individual should be able to receive support from the same service and if possible the same person throughout their recovery journey; in the case of MIFA member organisations, some have 20 year histories of support with certain people and would like to be able to support these persons (if the person so chooses) from pre-planning, through to support co-ordination, plan management and/or service provision. It is understandable that actual planning and access decisions must remain separate from service providers as this poses a potential conflict of interest, however, the evidence from MIFA consumers to date suggests consumers are needing and expecting a higher level of support throughout the access process than the NDIA or LAC planners can provide – the weight of which is being borne by existing programs set for transition.

Exit assumptions

The expectation from the NDIA (and its LAC agents) that people with severe and persistent mental ill health will quickly gain capacity has at times been unrealistic. Many of the people MIFA members support experience significant physical health complications, in addition to stigma, social isolation, poverty and low self-esteem. In one case example, a participant with a severe and persistent mental illness, complex medical conditions including a significant heart problem and uncontrolled diabetes, and an unhealthy lifestyle impacted by his mental health, was questioned as to why he had not gained independence after one year. This illustrates a lack of understanding on the part of NDIA planners about the significant challenges faced by those with ‘severe, persistent and complex’ issues – the very cohort that the NDIS was aimed at supporting. The lower rate of people exiting the scheme may be a result of unrealistic expectations for short-term interventions to improve functional outcomes.

²⁴ For more on continuity of care, see ‘Priority area 3: Service access, coordination and continuity of care.’ in Australian Government (2009) *Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009–2014*, [http://www.health.gov.au/internet/main/publishing.nsf/+content/9A5A0E8BDFC55D3BCA257BF0001C1B1C/\\$File/pla3.pdf](http://www.health.gov.au/internet/main/publishing.nsf/+content/9A5A0E8BDFC55D3BCA257BF0001C1B1C/$File/pla3.pdf)

The intersection with mainstream services

- *Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?*
- *How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?*
- *How will the full rollout of the NDIS affect how mental health services are provided, both for those who qualify for support under the scheme and those who do not?*
- *What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?*

Policy vacuum for psychosocial community supports

At the same time as ensuring that the NDIS scheme meets the needs of those for whom it was designed, it is imperative that the 225,000 people²⁵ not included in the NDIS are adequately planned for. There is significant unmet demand for psychosocial support, and significant barriers for people with psychosocial disability accessing the NDIS. Sector experience has demonstrated the programs that work best for people experiencing mental ill-health are those that are easily accessible with minimal assessment processes; highly flexible with the capacity to increase or reduce support as needed; and have elements of assertive outreach and wrap-around support. The population of people requiring psychosocial support can be divided into five groups:

1. Those eligible for NDIS, and have received an approved plan
2. Those eligible for NDIS, connected to program due for transition, and require support to apply
3. Those eligible for NDIS, but not currently connected to any services
4. Those ineligible for NDIS, but connected to a program that is due for transition
5. Those ineligible for NDIS, and not currently connected to any services

The sector remains deeply concerned about the particular cohort of people ineligible for the NDIS. The Department of Health has advised that Primary Health Networks (PHNs) are not to commission services for psychosocial support²⁶. MIFA welcomes the recent announcement of a Primary Health Network Advisory Panel on Mental Health, and hopes this will result in changes to PHN commissioning guidelines to bridge these gaps. While there have been assurances under the principle of continuity of service, in practice there is no clear indication of who and how the system will provide for those not eligible for the NDIS yet in existing programs, and more generally, those who were never Commonwealth clients to begin with. Members have reported emerging evidence of cost-shifting and ambiguities in responsibility, resulting in program uncertainty. For example, MIFA member One Door Mental Health reports that

²⁵ McGrath, D. (2016). *The Implementation and operation of the Psychiatric Disability Elements of the National Disability Insurance Scheme: A Recommended Set of Approaches*

²⁶ p6, Department of Health (2016). *PHN Primary Mental Health Care Flexible Funding Pool Implementation Guidance: Stepped Care*.

[http://www.health.gov.au/internet/main/publishing.nsf/content/2126B045A8DA90FDCA257F6500018260/\\$File/1PHN%20Guidance%20-%20Stepped%20Care.PDF](http://www.health.gov.au/internet/main/publishing.nsf/content/2126B045A8DA90FDCA257F6500018260/$File/1PHN%20Guidance%20-%20Stepped%20Care.PDF)

forensic consumer overnight leave services initially covered by the NDIS have been de-funded, with no resolution as to the relevant jurisdiction who holds responsibility²⁷. As noted above, maintaining loose eligibility criteria for the NDIS may result in inconsistent or arbitrary access decisions, and significant sustainability issues for the Scheme. On the other hand, failing to provide alternative programs for those outside the NDIS would result in the significant worsening of functionality for the cohort as a whole and create greater dependence on high level support in the future.

Transition of existing programs to the NDIS

MIFA, Mental Health Australia, and CMHA have advocated for the quarantining of mental health funding within the NDIS, and public tracking of program budget transition into the NDIS, to avoid repeating the loss of funding and poor transition of the 1980s deinstitutionalisation. This echoes the recommendations of the NMHC Review of Services that funding should follow the individual, and no more²⁸, meaning that the amount of funding moving into the NDIS from existing programs should be capped at the amount spent on that individual in the previous program. Programs rolled into the NDIS had much more accessible criteria, more assertive outreach capacity, and much greater flexibility of service than is possible under the NDIS. The experience of the roll out of NDIS has not alleviated concerns about funding shortfalls and loss of service among MIFA members and the mental health support sector as a whole.

Several of MIFA members are reporting delays and barriers transitioning participants to NDIS funding, with some programs at the point of closure. There has been some reprieve with a slowing down of transition percentages for some MIFA members (see One Door's submission), however, across the board services are reporting that the transition is running ahead of the number of people able to get plans. The effect is that block funding is being cut before NDIS packages are approved. In the meantime, employment stability and service continuity are affected. Some organisations try to continue services in this interim period, but incur a financial loss. Others have no option other than to close affected services. The flow of mental health funding (estimated at around \$1.8 billion to \$2 billion of the \$21 billion NDIS budget) should be tracked publically in a transparent manner. Furthermore, to ensure services can adequately plan for the future, and allow time for the full roll out of the NDIS and associated integration activities, the transition from block funding to NDIS packages should be stepped accordingly.

On the other hand, MIFA members have also reported significant positive outcomes for clients who have successfully gained plans. For example, MIFWA provided support to two people who formerly lived in the extremely restrictive environment of a psychiatric hostel. Through MIFWA's work, the two people were able to gain enough support to live back in their own home (a rented property), and therefore gain their independence, some financial freedom and

²⁷ See One Door's submission to the Inquiry into the Provision of Services , http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions

²⁸ NHMC (2014). Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services.

choice. In these cases, NDIS provided transformative change in their lives, due to regular practical support.

The transition of participants from existing programs in MIFA member organisations have revealed anywhere from 90% of people accessing an individual plan, to as low as 1% transition to NDIS (with the latter at the point of forcing closure of programs). However, the cost of the “success rate” in obtaining individualised plans for existing clients is very high. Intensive preparation, documentation and coaching of the individual, their family and all the supporting personnel such as GPs and Psychiatrists is only possible because the staff providing this support are funded from existing program contracts with government. This will not be the case after this funding ceases. This level of NDIS “success”, which often requires utilising the appeals process, is not sustainable. The barriers for people with a psychosocial disability in accessing the NDIS have been previously noted.

In Mental Health Australia’s submission, former MIFA CEO David Meldrum presented the following estimates on existing Commonwealth client eligibility for an individual plan: Day to Day Living (D2DL)– 50%, Partners in Recovery (PIR) – 70%. Current MIFA CEO Tony Stevenson estimates the Personal Helpers and Mentors Programs (PHaMs) will ultimately be able to transition around 40% of clients to NDIS individual plans, but figures could be lower or higher in certain areas.

Given the much broader access criteria for PHaMs, as well as the need to retain programs for carers separate to individual planning (such as the Mental Health Respite: Care Support (MHR-CS) program), MIFA is advocating that PHaMs and MHR-CS cease transition and be maintained as a separate program designed to meet at least some of the needs of the estimated 225,000 people without psychosocial support – regardless of how many existing clients successfully transition into the NDIS. MIFA is also advocating that 50% of D2DL funding and 30% of PIR funding be quarantined outside of individual support package funding and channeled into maintaining the same or similar programs. This would represent a dollar value in the order of \$365 million per year.

ILC & the LACs

- *Is the range and type of services proposed to be funded under the ILC program consistent with the goals of the program and the NDIS more generally?*
- *What, if anything, can be done to ensure the ILC and LAC initiatives remain useful and effective bridging tools between services for people with disability?*
- *Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? If not, how can this be improved?*

There is a clear need for integration between the NDIS and mainstream services, which is currently poor. As previously stated, MIFA has reservations about the ability of the LACs to provide all the support people with psychosocial disability require, and to also perform the complex role of networking between specialist mental health services. Preliminary reports from MIFA members indicate that LAC providers lack specialist psychosocial disability expertise; are

over-burdened with planning responsibilities; have not consulted specialist providers to assess integration needs; and there is little evidence NDIA planners (or their LAC agents) are referring clients back into other supports when found ineligible. Participants found ineligible for the NDIS should be linked directly back into other support services, via warm referrals. Overall, the communication between the NDIA (and its LAC agents), participants, their carers and support workers needs to be improved. Targeted training and networking is required to ensure general medical practitioners (GPs), allied health professionals, and those involved in inpatient discharge planning are aware of the services available under the NDIS.

There is strong potential for specialist, bulk-funded programs under the Information, Linkages and Capacity Building (ILC) component of the NDIS to address some of the gaps for those with psychosocial disability who are ineligible for an individual plan. Indeed, with the variability and inadequacy of other federal portfolio or State/Territory government taking responsibility for the psychosocial needs of the 225,000 people who will not be eligible the NDIS, ILC must step in to fill the vacuum. This is consistent with NHMC recommendations in the 2014 Review of Services report:

“The logic of Tier 2²⁹ should be that it is of sufficient capacity to support people whose psychosocial disabilities are not sufficiently “permanent” or profound[,] to live productive lives in the community and reduce their risk of entering Tier 3 due to worsening disability.”³⁰

The ILC is designed to support all people with psychosocial disability, whether or not they are eligible for the NDIS. Many of the outcomes for mental health recovery and the ILC are aligned, and in particular the Individual Capacity Building Activity in the ILC suggests individual psychosocial supports for those without a package may be in scope. Without permanency or high, complex needs eligibility criteria for the wider ILC program, there is potential for it to support a wide range of people. However, MIFA has strong reservations about the ability the ILC program to adequately fund such programs in its current formulation. Immediate action is required to quarantine funding for psychosocial services specifically, increase funding, clarify the funding criteria, and plan for integration between ILC programs, individual plans and other mental health supports, including PHNs, public and community health.

The total funding package for ILC at full roll out in 2019/20 is \$132 million, which when split across all types of disability is not adequate. MIFA, Mental Health Australia and CMHA have proposed quarantining \$365 million from the NDIS to support the continuation of key service elements of the PHaMs, PIR, MHR-CS and D2DL programs; this amount could be directly shifted and administered under ILC, assuming the Individual Capacity Building activity area of the ILC Outcomes Framework encompasses the kind of supports provided in these programs. Our strong recommendation is that the \$365 million is directed at PHaMs-like services that can

²⁹ Former term for ILC

³⁰ p62, NHMC (2014). Contributing lives, thriving communities Report of the National Review of Mental Health Programmes and Services.

respond quickly and flexibly without onerous assessment processes, PIR-like services that can assertively reach out to those with the most complex needs, and dedicated support for carers.

The ILC must provide greater clarity around the funding criteria. There are many ambiguities in ILC Policy that make it difficult for organisations providing psychosocial support to know how resources will be allocated. These include:

- Crossovers between outcomes for individual plans and the Individual Capacity Building activity of the ILC;
- Ambiguity between LAC functions and the potential work of other ILC programs, particularly as LACs are not yet widely operating;
- Contradictions between the ILC Commissioning Framework, which indicates commissioning will focus on diagnostic specific expertise and/or cohort-focused delivery³¹ (among other focus areas), while ILC documents elsewhere indicate that programs must benefit a wide range of people³²
- General ambiguity about the intent and focus of the funding, in particular the kinds of projects that are in scope

This lack of clarity has made it difficult for service providers to prepare funding bids or plan for future service delivery to clients. The short funding period and small amounts available disincentivise tendering. The focus in the ILC and LACs around mainstream service and broader community inclusion suggests a shift away from diagnostic specific expertise; there is concern about the ability of mainstream services to support those with psychosocial disability without strong partnerships or guidance from organisations with the experience, and consumer/carer connections to understand the needs of those with mental ill-health.

The roles and responsibilities of NDIS individually funded packages, programs funded under the Information Linkages and Capacity (ILC) program, LACs, PHNs, public and community health should be clearly delineated, with adequate resources to ensure that integration across services is possible.

³¹ ILC Commissioning Framework, p. 18

³² “We expect the activities we fund in ILC to benefit a wide range of people.” From <https://www.ndis.gov.au/ILC-FAQ-Organisations>

Planning processes

- *Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?*
- *Why is there a mismatch between benchmark package costs and actual package costs?*
- *Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?*
- *How should the performance of planners be monitored and evaluated?*
- *Are the criteria for participant supports clear and effective? Is there sufficient guidance for assessors about how these criteria should be applied? Are there any improvements that can be made, including where modifications to plans are required?*
- *To what extent does the NDIA's budget-based approach to planning create clear and effective criteria for determining participant supports? To what extent does it lead to equitable outcomes for participants? What improvements could be made?*
- *How well-equipped are NDIS-eligible individuals (and their families and carers) to understand and interact with the scheme, negotiate plans, and find and negotiate supports with providers?*

Plan utilisation has been primarily affected by participant difficulty in managing plans, the inclusion of inappropriate support items by planners, and the lack of locally available services. MIFA members report that participants often return to their MIFA support worker deeply confused about the content of their plan and the planning process in general. Previously mentioned barriers to access also apply to the planning process, such that participants may leave planning meetings feeling anxious, confused, and distressed. The language and structure of the plans is often foreign to participants. Over-the-phone planning meetings are particularly problematic for people with psychosocial disability. Decision-making about plan content is often not transparent, and it appears planners (in NDIA and LACs) are making diagnosis-driven assumptions about client needs, rather than assessing for functional impairment. Items are often included that are not needed, while other items that are almost always needed are left off (for example support co-ordination). The First Plan process resulted in rushed plans which may have included the wrong balance of Core/Capacity Building, and Capital supports.

Underspending of new plans may be a result of time taken to set up plan utilisation. There is often a lag time between when plans are approved and when service providers are selected and supports organised, and it can take time (and the help of a support co-ordinator) to get the optimal balance of supports. People who elected for self-management are often returning to the NDIA to request support co-ordination. Participants have also struggled to utilise plans due to a lack of appropriate providers with mental health experience and/or in rural and remote areas. In some cases, organisations selected by participants have been unable to deliver on contracted services due to lack of workforce availability or lack of skill to manage complex

clients. This has resulted in a lapse of service provision before participants were able to transfer to another service provider (and therefore an underspend in the intervening period).

In addition, severely unwell participants can struggle to undertake all the activities allocated in the plan. MIFA support workers will often work closely with these participants to creatively achieve the goals in their plans, however, as one service provider noted, *“The plan and NDIS does not make some people’s situations any less complex.”* Plans are not agile, and review processes have been slow. This is problematic for people with psychosocial disability, who may experience a sudden and rapid increase in support needs due to the episodic nature of mental health issues.

Many of the issues mentioned above may fall into the category of ‘teething issues’. As planners and participants achieve greater understanding of the NDIS, a higher percentage of allocated resources may be utilised. Nevertheless, close monitoring of these issues is required as they reflect systemic deficits in how the Scheme responds to people with psychosocial disability.

Pre-planning support is required, and should be provided by services who have visibility, diagnostic-specific expertise, and pre-existing connections with the community they serve. Planners need comprehensive training on psychosocial disability. The NDIA should work to ensure transparency of decision making around planning. Existing support people should be included in the planning process (whether informal carers or existing support workers). Communication with participants with a mental health issues should be conducted in a clear, timely manner, and where possible, face to face, so as to not further exacerbate mental health difficulties. Review processes need to be as agile as possible to ensure plans adequately match participant needs and reflect the fluctuating support needs of those with a psychosocial disability.

Market readiness

- *What factors affect the supply and demand for disability care and support workers, including allied health professionals? How do these factors vary by type of disability, jurisdiction, and occupation? How will competition from other sectors affect demand (and wages) for carers? What evidence is there from the NDIS trial sites about these issues?*
- *To what extent is the supply of disability care and support services lessened by the perception that caring jobs are poorly valued? If such a perception does exist, how might it best be overcome?*
- *Are prices set by the NDIA at an efficient level? How ready is the disability sector for market prices?*
- *How ready are providers for the shift from block-funding to fee-for-service?*

Service providers face many challenges in the transition to the Scheme. The financial uncertainty during the transition phase has severely impacted on service providers, with reports of several services closing in anticipation of funding cessation. Service providers are facing challenges transitioning the workforce to become mobile, casualised, autonomous,

reliable, and lower paid with more client contact time – while still retaining the many other skills required from mental health support workers. Even with complexity loading, the low cost margins and requirement for increased percentages of staff utilisation means staff are lower paid and have less time for supervision, training and professional development. Where previously skilled support workers were paid at SCHADS Levels 3, 4, 5 and 6, NDIS cost margins mean staff are employed at the much lower SCHADS Level 2, yet are required to work more autonomously with greater responsibility and less training and support. The nature of the NDIS and uncertainty of hours of work means much more people are employed on a casual basis impacting on uncertainty and job security.

Significant investment is required from service providers up-front to enter into the market, including staff training, marketing, and new financial, IT and client management systems. There are many hidden costs that service providers must account for, such as back-of-office support, and reimbursement for staff vehicle use to and from participants in the absence of a company fleet. All of these factors significantly impact on the viability of organisations seeking to provide supports to those most in need under the NDIS. Many organisations are relying on loss-leading strategies or current program funding set for transition to support the short-fall in income while waiting for participants to gain access to the NDIS. The uncertainty has stalled incentives for co-investment and limited desire to make capital investments. Some service providers feel fixed prices are stalling progress, as low prices do not enable service providers to reflect the true costs of service provision; others feel that providers are not ready for the NDIS, let alone market prices.

Conclusion

MIFA remains optimistic about the potential for the Scheme to provide long-lasting, transformative change to the people it supports. With clearer Scheme boundaries, mental health-sensitive implementation, support to providers during transition, and adequate funding for an integrated system beyond the NDIS, there is huge potential to provide services that truly meet the needs of those with psychosocial disability. MIFA thanks the Productivity Commission for the opportunity to provide input into the NDIS Costs Review. The commitment to ongoing improvement of the Scheme to ensure it supports those in greatest need is commendable.

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Disclaimer

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