

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

Submission to the Review of National Insurance Disability Scheme (NDIS) Costs – Productivity Commission Position Paper

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 60 'front doors' in metropolitan and regional areas, and support 20,000 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 (PC) in their review of the National Disability Insurance Scheme (NDIS) Costs. We welcome the opportunity to provide our input to the Productivity Commission Position Paper.

MIFA commends the PC on reflecting many of the concerns of stakeholders around the need to:

- improve access to the NDIS for psychosocial disability, with a suggestion for a psychosocial gateway (p144 of Position) and to provide better pre-planning support in general (p173 of the Position Position)
- have specialist planning teams (Draft Recommendation 4.2)
- properly fund the gap in services between NDIS and other psychosocial supports (p195 of the Position Paper)
- provide more funding for Information, Linkages and Capacity Building (Draft Recommendation 5.1) although MIFA considers the recommended increase inadequate MIFA has provided brief responses the recommendations in turn (see p16). We would also like to comment on the following matters:
 - Eligibility criteria for psychosocial disability (p144 of Position Paper)
 - Information request 4.1. reasonable and necessary definition
 - Information request 4.2. delegation of plan approvals to LACs
 - Information request 6.1. thin markets
 - Information request 7.2. impact on carer respite services
 - Information request 8.1. support coordination
 - Information request 8.2. role of disability support organisations
 - Information request 9.1. slow down of roll-out

Scheme eligibility - Psychosocial disability and the NDIS

MIFA notes that the PC has rejected stakeholder perspectives that permanency be removed from the eligibility criteria for psychosocial disability¹. MIFA maintains that the criteria for permanency in the context of psychosocial disability is inappropriate, as it is not based in prognostic evidence, is incongruent with recovery-oriented practice, and is unnecessary for ensuring the NDIS supports those most in need.

¹ p144, Productivity Commission Position Paper – NDIS Costs

There is no desire to make the criteria "less stringent"² for people with psychosocial disability; indeed, MIFA has repeatedly advocated that the NDIS must target those *most* in need, and adopt strategies to ensure the costs of the NDIS do not blow out by inadvertently including a larger cohort of people than those for whom the scheme was designed³.

We recommend the criteria for permanency is removed in the context of psychosocial disability in order to overcome the significant definitional barriers for people with psychosocial disability; while maintaining the other elements of the criteria and placing a greater emphasis on current and historical functional impact.

Is permanency a barrier?

The PC notes that there are currently 5000 people with psychosocial disability in the scheme, citing this as evidence that the definition does not present barrier for people accessing the scheme⁴. They further note that 81% of people who have made access requests have been found eligible⁵. These two statistics have also been cited by the Department of Social Services as evidence that people with psychosocial disabilities are able to "participate in the same way as people with other significant and permanent disabilities."⁶

However, these statistics do not provide convincing evidence that the eligibility criteria are not a barrier. These numbers do not acknowledge the significant number of people who are choosing not to apply (MIFA members report between 17% and 37% of participants in PIR programs⁷), meaning the true eligibility rate for people in Partners in Recovery (PIR) may be closer to 60%. Participants are choosing not to apply, in part, due to the requirement for permanency, based on issues providing evidence to that effect and to philosophical issues with the criteria.

These statistics also do not acknowledge that significant barriers have been overcome through the support of community mental health providers to gain access to the NDIS, including advocacy to health professionals to understand how the NDIS expects "permanency."

MIFA has gathered case studies of participants being rejected on the grounds that the person's health professional mentioned the possibility of recovery in their supporting evidence; or on the grounds that their diagnosis is not a permanent condition – in particular, people with bipolar and

² p144, Productivity Commission Position Paper – NDIS Costs

³ p6, MIFA Submission No. 122 Available at: http://www.pc.gov.au/ data/assets/pdf_file/0008/215747/sub0122-ndis-costs.pdf

⁴ p143, Productivity Commission Position Paper – NDIS Costs

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⁶ Evidence given by John Riley, Acting Group Manager, NDIS Market Reform Group, Department of Social Services, to the Joint Standing Committee on the NDIS – Mental Health inquiry, Public Hearing 16 Jun 2017. Available at: http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommint%2F49e https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommint%2F49e https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommint%2F49e https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommint%2F49e https://parlinfo.aph.gov.au/parlinfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommint%2F49e https://parlinfo.aph.gov.au/parlinfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommint%2F49e <a href="https://parlinfo.aph.gov.au/parlinfo/search/display/dis

⁷ p4, One Door Mental Health (2017). Post- Paper Submission 226, Available at: http://www.pc.gov.au/ data/assets/pdf file/0018/219321/subpp0266-ndis-costs.pdf

other mood disorders. Psychosocial disability has the lowest rate of successful access requests⁸, and trial site evaluations showed that those with PTSD, depression & mood disorders are more likely to be declined a package.⁹ 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.¹⁰ There is also evidence showing that while these disorders are commonly considered 'less severe', they are significantly disabling for a large percentage of people¹¹, providing further evidence that diagnosis-driven decision-making must be avoided.

Other reported barriers can occur once a person has gained access. In one case example, a participant received access to the NDIS, and attended his planning meeting, during which he refused to characterise his illness as permanent as he found that discouraging and offensive. His access to the NDIS was consequently reviewed.

The issue of definitional alignment is so widespread that the new *reimagine* website designed to support people with mental health issues to access the NDIS includes a section advising participants they must shift their recovery beliefs in order to fit with the National Disability Insurance Agency (NDIA)'s definitions¹².

There is certainly disagreement in the sector around whether permanency is a barrier for people with psychosocial disability, as noted by the PC¹³. There are some participants who like the stability and finality that a "permanent" diagnosis brings them¹⁴. Some advocates are comfortable with the inclusion of permanency because they are reading the early intervention requirements as moderating the need for permanency¹⁵ – however, the early intervention requirements are clear that the impairment itself must still be permanent. A person can access early intervention if their *need for support* isn't permanent; they still need to have a permanent impairment. Furthermore, anecdotal reports suggest that few people with psychosocial disability are entering the scheme under early intervention requirements.

In order to better understand these barriers, the NDIA should undertake, as a matter of priority, a comprehensive analysis of access decisions (both accepted and rejected) in the context of psychosocial disability, including a finer level of analysis to disaggregate the factors supporting the decision, such as presence and type of diagnosis, functional impact and domains of impact,

http://www.pc.gov.au/ data/assets/pdf file/0016/215413/sub0063-ndis-costs.pdf

⁸ 71.3% in Q2, Oct-Dec 2016. p56. National Disability Insurance Agency (NDIA) (2017). *COAG Disability Reform Council Quarterly Report Q2 2016-17*. Available at:

https://www.ndis.gov.au/medias/documents/hda/h8d/8800076922910/CDRC-Report-2016-17-Q2.pdf

⁹ 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

¹⁰ 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

¹¹ Available at: http://ps.psychiatryonline.org/doi/pdf/10.1176/appi.ps.53.1.80

¹² Reimagine website (2017). Mental health recovery, psychosocial disability and the NDIS. http://reimagine.today/step-1/mental-health-recovery-psychosocial-disability-and-the-ndis/

¹³ p143, Productivity Commission Position Paper – NDIS Costs

¹⁴ https://waamh.org.au/news/permanency-requirement-draws-mixed-reactions.aspx

¹⁵ See for example, p4, Submission 63, available at:

evidence for past and present treatment, previous program if transitioning, and any other factors relevant to understanding the cohort of people accessing the NDIS.

MIFA maintains that permanency presents a significant barrier because it is not evidence-based, is inconsistent with recovery principles, and is unnecessary in the context of psychosocial disability. The reasons for our position will be outlined below.

Are mental illnesses permanent?

There are no clear diagnostic or other factors that can reliably predict whether a person will be permanently impaired by a mental health condition, or require permanent support. The Mind Literature review commissioned by the Independent Advisory Council (IAC) to the NDIA¹⁶ presented research that a subset of people with schizophrenia will never completely "recover" (in a psychiatric sense of no symptoms), and that there are researched indicators that may enable prediction of whether a person will have ongoing impairments.

While it may be true that a subset of people never recover, the evidence for rates of recovery in mental health conditions is highly inconsistent. For example, one review showed at least 1 in 7 people with schizophrenia fully recover, but results varied with some studies reporting as high as 1 in 3 or 1 in 2 people fully recovering from schizophrenia¹⁷.

Furthermore, while some factors, such as age of onset or baseline functioning, may be predictors of poor prognosis over a lifetime, there are few that have high predictive power. This means that although factors may be associated with better outcomes, they are not able to actually predict with a high reliability who will and who will not be permanently impaired. For example, in Austin et. al. (2013), even a multifactorial model including a range of predictors (such as baseline functioning and negative symptoms) found 78% of full recovery in psychotic illness is explained by other, unknown factors¹⁸.

It is not uncommon for predictive factors in psychology to have low effect sizes, given the complexity of human behaviour; these predictors may be significant in a statistical sense, and considered adequate from a research perspective. However, from a clinical perspective, the research evidence is too heterogenous and the effect sizes too small to accurately predict the course and outcome of someone's mental illness^{19,20}. It is difficult, if not clinically inaccurate, therefore, for health professionals to give evidence to that effect.

¹⁶ Nicholas, A., Reifels, L., King, K., and Pollock, S. (2014). *Mental Health and the NDIS: A Literature Review*. Available at: https://www.ndis.gov.au/html/sites/default/files/files/Mental-health-and-the-NDIS-Literature-Review.pdf

¹⁷ Jaaskelainen et al. (2012). 'A systemic review and meta-analysis of recovery in schizophrenia.' *Schizophrenia Bulletin.* 39(6), pp1296-1306. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3796077/

¹⁸ Austin, et. al. (2013.) 'Predictors of recovery in first episode psychosis: The OPUS cohort at 10 year follow-up.' Schizophrenia Research, 1(150), pp163-168. Available at:

 $[\]underline{\text{http://schizophrenia.elsevierresource.com/articles/predictors-recovery-first-episode-psychosis-opus-cohort-10-year-follow/fulltext\#back-bb0240}$

¹⁹ Chen, H., Cohen, P., and Chen, S. (2009). 'How Big is a Big Odds Ratio? Interpreting the Magnitudes of Odds Ratios in Epidemiological Studies.' *Journal of Communication in Statistics – Simulation and Computation*, 39 (4), available at: http://www.tandfonline.com/doi/abs/10.1080/03610911003650383

²⁰ Cohen, J. (1988). Statistical Power Analysis for the Behavioral Sciences. Routledge.

Recovery-oriented practice

Health professionals can be unwilling to provide evidence that an impairment is or is likely to be permanent, both because this may be clinically impossible to predict, but also because it is at odds with a recovery framework. This is particularly true for health professionals who do not subscribe to an organic or medical model of mental illness. In the context of psychosocial disability, motivation and self-belief may have an independent and significant role in generating better outcomes for participants²¹. Stating that someone has a permanent impairment may not only be clinically inaccurate, but may be harmful.

Many stakeholders, including MIFA, believe that permanency is incongruent with a recovery-oriented model. The recovery oriented model is well articulated in the principles *National Framework for Recovery-Oriented Mental Health Services*, endorsed by the Australian Health Ministers' Advisory Council in 2013²². The recovery model is founded in the principles that *recovery is possible*, that hope and empowerment are essential, and that mental health is a deeply personal journey in which one's own understanding and language around one's experience is central. Some have argued that there is significant alignment between the NDIS principles of rights, choice and control, and recovery principles, as has been explored elsewhere²³, and MIFA acknowledges the internal and external work that the NDIA has done to reconcile these differences and support access processes²⁴. However, we still maintain that requiring participants and health professionals to characterise mental health conditions as permanent is fundamentally antithetical to recovery principles.

Many participants in MIFA member programs say that the label "permanently impaired" is demoralising, and even insulting and denigrating. Many workers who operate from a recovery framework are similarly highly critical of its use, because it denies participants hope and may make them less motivated, and therefore less likely to recover.

Janet Meagher, expert advisor to the IAC and key advocate in the lived experience and recovery movement, gave the following evidence to the Joint Standing Committee on the NDIS:

"Ideologically, I cannot see how recovery is aligned to permanency ... permanency has very little to do with recovery; it has everything to do with hope." ²⁵

²¹ Horan, W. et. al. (2010). 'Further Support For the Role of Dysfunctional Attitudes in Models of Real-World Functioning in Schizophrenia.' *Journal of Psychiatric Research*, 44(8), pp.499-505. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3414437/#!po=9.28571

²² Department of Health (2014). National framework for recovery-oriented mental health services. Available at: http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-recovfra

²³ 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

²⁴ Including the pending Best Practice Guide for Access to the NDIS, public factsheet "Psychosocial disability, recovery and the NDIS", guide "Completing the access process for the NDIS: Tips for Communicating about Psychosocial Disability", and reimagine website.

²⁵ Evidence given by Janet Meagher, IAC expert, to the Joint Standing Committee on the NDIS – Mental Health inquiry, Public Hearing 28 April 2017. Available at:

 $[\]frac{\text{http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id\%3A\%22committees\%2Fcommjnt\%2F24d}{13a89-fe9a-4292-ad38-971691d03471\%2F0000\%22}$

Professor Pat McGorrie, Professor of Youth Mental Health at The University of Melbourne, Executive Director of Orygen (the National Centre for Excellence in Youth Mental Health), and expert in early psychosis and youth mental health, gave evidence to the same inquiry which explained the difficulty and potential unhelpfulness of attributing permanency:

"The way mental illness causes disability, as Frank [Quinlan, CEO of Mental Health Australia] was alluding to, is somewhat different. There are some people where is does have a permanent and long-term effect. Certainly, the way we work with youth mental health and early intervention is that we do not want to assume that is going to be the case, even though it does end up being the case for a substantial minority of the young people that do develop these serious illnesses. Our aim is to achieve recovery. A very important thing in psychiatry is early intervention and recovery ... and changing the pessimism that used to be associated with these illnesses. To have a model that assumes and requires permanent and fixed disability does not really work for us; certainly not in youth mental health. This is what young people have told us. ²⁶

The idea that the impairments experienced because of mental ill-health are intrinsic, physically founded and un-changeable is not supported by clinical research and is in direct contradiction to recovery principles, which hold that impairments are changeable and fluctuating; and that through external supports and internal resources, individuals can achieve wellness and even completely recover.

Other misalignments with permanency

The issue of whether permanency can apply to psychosocial disability is further complicated by the effect of psychosocial support on mental health impairment. Indeed, with the right supports, it is arguable that impairments may diminish to the extent that the impairment no longer exists. This does not negate that a person may have been significantly and severely impaired for many years prior. The effective management of symptoms through capacity building and an ongoing, although hopefully lower, level of supports is the goal of recovery, even in cases where someone has severe and enduring mental illness. This contrasts with physical impairments, where the impairment itself will patently exist for life, while only the *functional impact* of the impairment will vary dependent on the supports the person receives and the level of internal capacity.

Psychosocial disability also operates differently insofar as medical and clinical supports are likely to be required ongoingly, which can cause confusion with regards to the *NDIS* (*Becoming a Participant*) Rules 2016, Rule 5.4, which states that there must be "no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment"²⁷. In the context of psychosocial disability, this condition can be met by providing evidence that a person has received adequate treatment and that their condition is

²⁶ Evidence given by Professor Pat McGorrie, to the Joint Standing Committee on the NDIS – Mental Health inquiry, Public Hearing 28 April 2017. Available at:

 $[\]frac{\text{http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id\%3A\%22committees\%2Fcommjnt\%2F24d}{13a89-fe9a-4292-ad38-971691d03471\%2F0000\%22}$

²⁷ NDIS (Becoming a Participant) Rules 2016 (Cth). Available at: https://www.legislation.gov.au/Details/F2017C00121

stable, but how this is best evidenced remains to be clarified by the NDIA. There are also overlaps between what is considered psychosocial support and what is considered clinical treatment (for example, behavioural interventions).

Is permanency necessary?

MIFA acknowledges the PC's concerns around "relaxing" the eligibility criteria for people with psychosocial disability. As noted by the PC, boundaries are important²⁸ and the financial sustainability of the scheme must be protected. However, these arguments do not support maintaining false boundaries that do not reflect the clinical evidence, or the lived experience of the people who the NDIS aims to support.

MIFA maintains it is possible to delineate the cohort of people requiring support under the NDIS – that is, those with severe and enduring mental illness, significant impairments in functioning, and requiring extensive supports to maintain their life outside institutional care²⁹ - without reference to permanency. This can be achieved through a strong focus on the level of functioning, and the need for support. The cohort of people requiring support under the NDIS are able to provide evidence of severe functional impacts, and evidence of the need for ongoing, high level supports. It is also possible for them or their treating health professional to describe previous attempts at treatment and the current treatment. These factors combined are adequate to identify the cohort of people with severe mental illness and complex support needs, without requiring that someone's condition be permanent.

Other systems have overcome the limitation of permanency by providing clear, working definitions around the meaning of permanent; for example, the *Social Security Act 1991*, which uses the definition of "likely to persist for more than two years" and "not likely to improve in the next two years"³⁰. This standard of evidence may be too low for the NDIS, which provides lifetime entitlements.

McGrath (2016) suggested that in the context of psychosocial disability, a change in the eligibility criteria may require a change in the presumption of lifetime support³¹. In terms of managing boundaries, there are no additional risks from including someone who has a severe and enduring mental health condition, versus someone who has permanent mental health condition. Where the need for support diminishes, plan reviews will reduce packages accordingly, enabling a reduction in costs.

MIFA, Mental Health Australia, and Community Mental Health Australia put forward an options paper to the Joint Standing Committee on the NDIS for addressing the permanency criteria for

http://www.aph.gov.au/DocumentStore.ashx?id=2102830b-fade-440f-b4e1-c498d1a70490&subId=461257

²⁸ p143, Productivity Commission Position Paper – NDIS Costs

²⁹ p754-p755 , PC (2011). Disability Care and Support: Productivity Commission Inquiry Report, 54(2), Canberra

³⁰ Section 6(4), 6(4), and 6(5). Social Security (Tables for the Assessment of Work-related Impariment for Disability Support Pension) Determination 2011 (Cth). Available at: https://www.legislation.gov.au/Details/F2011L02716

³¹ 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:

people with psychosocial disability (Appendix A). This included a recommendation to replace the word *permanency* with *ongoing*, *enduring*, or *chronic*. It further notes that the *NDIS Act* is due for review³². Operationally, targeting the right group of people with severe and enduring psychosocial disability might require identifying a recommended length of time that impairment has been experienced in the past, and/or a length of time they are likely to be experienced into the future. Alternatively, evidence of previous long-term need for support and likelihood of need for support into the foreseeable future might be satisfactory.

Responses to information requests

INFORMATION REQUEST 4.1

Is the National Disability Insurance Scheme Act 2013 (Cwlth) sufficiently clear about how or whether the 'reasonable and necessary' criterion should be applied? Is there sufficient clarity around how the section 34(1) criteria relate to the consideration of what is reasonable and necessary? Is better legislative direction about what is reasonable and necessary required? If so, what improvements should be made? What would be the implications of these changes for the financial sustainability of the scheme?

In the experience of MIFA's members, the definition of reasonable and necessary has been too vague and ambiguous to provide operational clarity for planners and for those seeking to obtain packages. There is significant evidence of inconsistent packages across Australia. The NDIA should continue to provide clarity through public resources that give practical examples (for example, by continuing to add to the reimagine website³³ with case examples and sample plans).

The creation of reference packages for people with psychosocial disability may also support a better understanding of what supports are consistently required for people with psychosocial disability, and what is considered not only reasonable and necessary, but best practice in terms of supporting people to move to higher levels of functioning. For example, support coordination is an integral part of enabling people to navigate their plans and continue to set goals. Case law may also continue to provide precedents, although this is a costly mechanism for seeking clarity. Legislative changes may be required to provide further clarity. MIFA notes that a review of the NDIS Act is now due, as recommended by Ernst and Young in their 2015 review of the NDIS Act³⁴.

INFORMATION REQUEST 4.2

Should the National Disability Insurance Agency have the ability to delegate plan approval functions to Local Area Coordinators? What are the costs, benefits and risks of doing so? How can these be managed?

While positions vary, generally MIFA members do not support this proposition. Although it may reduce the administrative burden on the NDIA, and potentially lead to faster plan approval and review processes, there is significant concern about the current workforce expertise and capacity of Local Area Coordinators (LACs). LACs are not specialised in psychosocial disability, and their

https://www.dss.gov.au/sites/default/files/documents/04_2016/independent_review_of_the_ndis_act.pdf

³² p3, Ernst and Young. (2015) *Independent Review of the NDIS Act.* Available at:

³³ Reimagine website (2017). Mental health recovery, psychosocial disability and the NDIS.

http://reimagine.today/step-1/mental-health-recovery-psychosocial-disability-and-the-ndis/ p3, Ernst and Young. (2015) *Independent Review of the NDIS Act.* Available at:

https://www.dss.gov.au/sites/default/files/documents/04 2016/independent review of the ndis act.pdf

role in planning may be further exacerbating their conflicting priorities and increasing the level of distrust participants (particularly those with psychosocial disability) feel towards them. Devolving plan approvals to LACs may further complicate their role.

There is also concern that quality control in approval and planning processes is already lacking. Central NDIA planning approvals appear to operate as a rubber stamp, whereas a greater role in quality-checking and benchmarking plans is needed to reduce national inconsistency and ensure the suite of supports offered are best practice for people with psychosocial disability. Removing all oversight, while time-saving, is likely to worsen the quality of plans.

INFORMATION REQUEST 6.1

In what circumstances are measures such as:

- cross-government collaboration
- leveraging established community organisations
- using hub and spoke (scaffolding) models
- relying on other mainstream providers

appropriate to meet the needs of participants in thin markets? What effects do each have on scheme costs and participant outcomes? Are there barriers to adopting these approaches?

Under what conditions should block-funding or direct commissioning of disability supports (including under 'provider of last resort' arrangements) occur in thin markets, and how should these conditions be measured?

Are there any other measures to address thin markets?

MIFA members recommend leveraging the significant expertise and connection with community available in established community organisations to block fund providers of last resort. Understanding the antecedents to thin markets is important in addressing them — a key driver of thin markets is inadequate pricing. Participants with psychosocial disability in the NDIS require (by virtue of being eligible for the NDIS) specialised supports, which require a high level of worker training and supervision to provide.

INFORMATION REQUEST 7.2

How has the introduction of the National Disability Insurance Scheme affected the supply and demand for respite services? Are there policy changes that should be made to allow for more effective provision of respite services, and how would these affect the net costs of the scheme and net costs to the community?

Capacity building supports for individuals within NDIS plans can provide respite for carers. NDIS pricing generally provides inadequate overheads to support the capital investment required to maintain off-site overnight respite services for carers; however, flexible respite in the form of relieving carers for a night in the family home is accessible under the NDIS. There are significant challenges with maintaining group-based or clubhouse style models of support under the NDIS, due to inadequate pricing structures and difficulties with managing fee-for-service when attendance is unpredictable. Planners are also failing to properly consider the needs of carers when formulating plans, and participants, planners and support coordinators may not always recognise that supporting carers to have respite also progresses other participant goals, such as ensuring participants have informal support that is sustainable and enduring. The NDIA and its agents need to ensure carers are adequately considered as a holistic part of the participant's journey.

In addition to the supports available under the NDIS, there is an ongoing need for carer support outside of individual plans – in particular, information, referral, peer support groups, counselling and one-on-one support. These should be provided in a consistent way across jurisdictions via additional investment in carer support programs in the Information, Linkages and Capacity Building (ILC). MIFA is also advocating maintaining the Mental Health Respite: Carer Support program outside the NDIS to enable continuity of support for carers where the participant is ineligible for a plan, or does not want to apply, as well as providing flexible entry for carers that does not require the stringent NDIS access process. This is particularly important as often carers are the first to reach out for support, and can be instrumental in supporting individuals to access services (noting that around 54% of people with mental ill-health do not seek help)³⁵.

INFORMATION REQUEST 8.1

Is support coordination being appropriately targeted to meet the aims for which it was designed?

There is an expectation from the NDIA that all participants should be able to move to lower levels of support coordination rapidly, and cease to require support coordination altogether at a point. MIFA cautions against these short-term expectations of support coordination. In the context of psychosocial disability, MIFA members have noted that support coordination is critical, should be a fundamental part of someone's plan, and ongoing (even if at a lower level) for the life of a plan. This investment is likely to ensure that plans are implemented by participants with the greatest potential for success. Support coordinators also play a significant role in empowering participants to report on the success of their plan, and set goals for plan reviews.

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' issues³⁶ – the very cohort that the NDIS was designed to support.

Many participants also require support with the interface between clinical support, housing providers, welfare, and other systems. The need for case management was identified as an important part of the Partners In Recovery (PIR) model³⁷, and often lacking for people with psychosocial disability. Systemic advocacy and multiagency coordination was also a core feature of the Support Facilitator role in PIR. There are mixed views about the role of NDIS Support Coordination in providing systems navigation, and one step further, systemic advocacy. There is

³⁵ Whiteford HA, Buckingham WJ, Harris MG, et al. Estimating treatment rates for mental disorders in Australia. Australian Health Review 2014; 38(1): 80-5.

³⁶ p754-p755, PC (2011). Disability Care and Support: Productivity Commission Inquiry Report, 54(2), Canberra.

³⁷ Urbis (2015). Partners in Recovery Annual Report 2014-15.

 $[\]frac{\text{http://www.health.gov.au/internet/main/publishing.nsf/content/FA19DF60B8CA6904CA25802800127C1D/\$File/annual15.pdf}{\text{nnual15.pdf}}$

increasing recognition that complex care coordination is essential to overcoming multiagency communication issues, delays and/or duplication in service delivery, reducing safety risks³⁸. Given the NDIS is targeted at people with psychosocial disability whose "complex needs requiring coordinated services from multiple agencies"³⁹, it follows that care coordination is a necessary and essential part of their ongoing support. Many participants in MIFA member programs have also argued that they want their support coordinator to come from the same organisation that provides their other supports, due to their familiarity and level of trust in that organisation (a relationship that in some cases, has endured for over 20 years). This is also aligned with best practice which supports the concept of continuity of care⁴⁰. It is possible to manage any conflicts of interest this may pose.

MIFA members report concerns about lack of quality in the provision of support coordination by some providers. This is due to a lack of market stewardship and operational oversight of quality on the part of the NDIA. There has been an increase in providers offering support coordination, in part due to the financial incentives associated with the pricing of support coordination line items. Members report concern that services are being offered by staff with no previous disability experience, let alone experience in case management, empowerment and recovery principles. MIFA advocates greater clarity and communication from the NDIA around the role and underlying principles of support coordination, as well as greater communication to participants about the standards to be expected from their support coordinator to ensure choice and control. The NDIA document, "Coordination of Supports: Information for Providers" ⁴¹ provides more clarity than other publicly available documents⁴². There should also be quality checking and performance management systems to ensure support coordinators are meeting the expectations of the role. For example, support coordination should be conducted face to face and in conjunction with participants wherever practicable. Support coordination should emphasise "doing with", rather than "doing for" participants, and at every step should empower participants to self-advocate for their needs.

MIFA members have developed resources to guide their own quality provision of support coordination in the context of psychosocial disability. It is essential that the NDIA draws on the

Department of Health (Cth) (2016). Health Care Homes: for health professionals – Why is this a priority?
 Available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes-professional
 ³⁹ p14. Australian Government Actuary (2012). NDIS Costings – Review by the Australian Government Actuary. Available at:

 $[\]frac{\text{http://www.treasury.gov.au/}^{\text{media/Treasury/Access}\%20to\%20Information/Disclosure\%20Log/2012/National\%2}{\text{ODisability}\%20Insurance\%20Scheme\%20Costings\%20Review\%20by\%20the\%20Australian\%20Government\%20Actu}{\text{ary/Downloads/PDF/doc1.ashx}}$

⁴⁰ 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*,

 $[\]underline{http://www.health.gov.au/internet/main/publishing.nsf/+content/9A5A0E8BDFC55D3BCA257BF0001C1B1C/\$File/pla3.pdf}$

⁴¹ Version 1.0, December 2015 – not available online

⁴² For example, Support Coordination: Information for Providers (March 2017). NDIA Factsheet. Available at: https://www.ndis.gov.au/medias/documents/hdf/hc6/8800436518942/Fact-sheet-Support-coordination.pdf

significant expertise of service providers who have worked with these cohorts over long periods of time, when developing guidelines and quality checking mechanisms.

INFORMATION REQUEST 8.2

Is there scope for Disability Support Organisations and private intermediaries to play a greater role in supporting participants? If so, how? How would their role compare to Local Area Coordinators and other support coordinators? Are there any barriers to entry for intermediaries? Should intermediaries be able to provide supports when they also manage a participant's plan? Are there sufficient safeguards for the operation of intermediaries to protect participants?

MIFA has ongoing reservations about the ability for LACs to meet the needs of people with psychosocial disability in accessing and navigating the NDIS. These include several stages of support:

- 1. assertive outreach into the community, a phase of building trust;
- 2. significant pre-planning support to assist with participant preparedness, including evidence gathering;
- 3. support throughout the access request and planning process, including advocacy and supported decision-making;
- 4. support co-ordination to co-ordinate NDIS supports;
- 5. ongoing support navigating mainstream services a broader view of support coordination.

LACs already have an extensive remit (both planning and networking), and lack specialist psychosocial expertise.

MIFA supports the idea of a psychosocial gateway⁴³, which would need to be properly funded to fully meet these needs. However, we note that this may only address point 3 above – better support throughout the access request and planning process. There is a need for dedicated, specialised and integrated support around the entire process of NDIS access and navigation for people with psychosocial disability. Disability Support Organisation could continue to play a role in this space, in light of their visibility, diagnostic-specific expertise, and pre-existing connections with the community they serve. Partners in Recovery (PIR) is a pre-existing, successful program with the infrastructure, specialist expertise and workforce capability, and level of engagement with the community to meet these needs. It is currently supporting clients in this capacity during transition, and should be funded to continue beyond the transition date, potentially through ILC funding.

PIR incorporates a strong assertive outreach framework, which works through contemplative and pre-contemplative⁴⁴ resistance to help-seeking – including resistance to NDIS applications. Evaluations of PIR have shown assertive outreach strategies are successfully able to connect with excluded cohorts, including people experiencing homelessness and Aboriginal and Torres Strait

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⁴³ p144, Productivity Commission Position Paper – NDIS Costs

⁴⁴ 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

Islander people^{45,46} . PIR also co-ordinates with mainstream services. Individuals with psychosocial disability often have severe comorbid conditions, and may have stabilised in their treatment but will continue to receive support from clinical and medical supports. As previously mentioned, complex care coordination is increasingly recognised as essential to achieving good outcomes.

It should be noted that when stakeholders describe the gap emerging as programs are rolled into the NDIS, we are referring not only to the gap in services for those ineligible, but to the type of service and features of programs rolled in to the NDIS that that we believe need to be retained. These features are difficult or impossible to provide under the individual fee-for-service model. These include:

- a) flexible entry requirements and no lag-time in support;
- b) assertive outreach or assertive engagement;
- c) ability to be flexible in kinds and length of support provided;
- d) individual systems navigation and multiagency care co-ordination; and
- e) system reform and cross-sector collaboration.

These services need to continue to be provided to people within the NDIS and to those ineligible, whether via LACs (noting previous reservations), ILC block funding to Disability Support Organisations, or other ex-NDIS funded programs (e.g. the recently announced Commonwealth Department of Health Psychosocial Support Program).

The current level of funding under the ILC is inadequate. Even with Draft Recommendation 5.1 to roll-out the funding to the full amount early, with the full range of other disabilities requiring services under the ILC, psychosocial disability stands to only receive a very small amount of the \$131m in funding. Indeed, in the latest round of the National Readiness Grants for ILC, only one mental health organisation received funding⁴⁷. Programs funded under the ILC need to have national coverage to provide individual information, referral and connection to mainstream supports, individual capacity building, as well as community education, mainstream capacity building, and stigma reduction, in order to meet the outcomes of the ILC.⁴⁸

As previously noted, the LACs cannot operate in the specialist manner required for psychosocial support. It is appropriate to have independent Disability Support Organisation workers and other intermediaries strongly engaged in supporting individuals throughout the access and planning process, and where appropriate, through to coordinating an individual's NDIS supports and their ongoing access to mainstream services.

⁴⁵ 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

⁴⁶Urbis (2015). *Partners in Recovery Annual Report 2014-15.*

 $[\]frac{\text{http://www.health.gov.au/internet/main/publishing.nsf/content/FA19DF60B8CA6904CA25802800127C1D/\$File/annual15.pdf}{\text{nnual15.pdf}}$

⁴⁷ http://www.disabilityservicesconsulting.com.au/resources/ilc-national-grants

⁴⁸ NDIA (2016). *Information, Linkages and Capacity Building (ILC) – Outcomes Framework Discussion Starter.*Available at: https://ndis.gov.au/medias/zip/documents/h0c/h0c/8799178719262/ILC-Outcomes-Framework-Web-Version-17.11.2016.docx

Disability support organisations also play a strong and significant role in amplifying the voice of lived experience, and nurturing and maintaining the peer workforce. The importance of this should not be underestimated. Peer support workers are ideal for connecting with disengaged people, and ensure that lived experience is embedded in service design and delivery. Supporting a peer workforce requires additional supervision and mentoring, and additional workplace flexibility - but it is worth it. Advocacy emerging from the direct experiences of consumers and carers is essential to the functioning of civil society.⁴⁹

As previously noted, the role for advocates in the NDIS system (including in the support coordination role) has been largely ignored. The tight operating margins emerging from the NDIS pricing is also reducing the capacity for organisations to devote resources to system advocacy. Many MIFA members were established as peer networks of concerned consumers and carers advocating for better services for people with schizophrenia and other severe mental illness⁵⁰. MIFA itself was formed in 1986 as the Schizophrenia Council of Australia, with a core function of systemic national advocacy. This role has been considered so important by MIFA members that it has continued in this capacity, mostly member-funded, for over 30 years. MIFA and its members continue to advocate for service improvements and the inclusion of lived experience, and provide training and opportunities for consumers and carers to be involved in systemic change. MIFA strongly supports any efforts to involve advocacy organisations in the governance and design of the NDIS, and provide more resources to organisations to support advocacy activities either as part of other services or as their sole focus.

INFORMATION REQUEST 9.1

The Commission is seeking feedback on the most effective way to operationalize slowing down the rollout of the National Disability Insurance Scheme in the event it is required. Possible options include:

- prioritising potential participants with more urgent and complex needs
- delaying the transition in some areas
- an across-the-board slowdown in the rate that participants are added to the scheme.

The Commission is also seeking feedback on the implications of slowing down the rollout.

MIFA notes that this would need to be carefully managed, as there are many community members in urgent need of support. Eligible participants are already experiencing significant delays while navigating access and first planning processes; delaying access to additional areas may be inequitable. It is important not to compromise the quality of support provided, however, it is equally important to ensure timely access to the NDIA. Providing additional supports to providers and assigning additional resources to the NDIA may support roll-out.

⁴⁹ Eikenberry, A., & Kluver, J. (2004). The Marketization of the Nonprofit Sector: Civil Society at Risk? *Public Administration Review*, 64(2), 132-140. Available at: http://community-wealth.org/sites/clone.community-wealth.org/files/downloads/article-eikenberry.pdf

⁵⁰ See, for example, https://www.skylight.org.au/index.php/about-skylight/history, https://www.skylight.org.au/index.php/about-us/history, https://www.skylight.org.au/index.php/about-us/history, https://www.skylight.org.au/index.php/about-us/history, https://www.skylight.org.au/index.php/about-us/history

Responses to recommendations

Scheme eligibility

DRAFT RECOMMENDATION 3.1

When determining that an individual is eligible for individualised support through the National Disability Insurance Scheme under the disability requirements, the National Disability Insurance Agency should collect data on which of the activity domains outlined in section 24 of the National Disability Insurance Scheme Act 2013 (Cwlth) are relevant for each individual when they enter the scheme.

Endorse, noting that:

There are a number of additional indicators that should be collected to understand access decisions, including: information about rejected access decisions, including reasons for rejection; presence and type of diagnosis; functional impact and domains of impact; what level of treatment to be considered eligible; previous program if transitioning; supports required (pre- and post- entry into the NDIS, based on National Mental Health Service Planning Framework service elements or National Minimum Data Set collection); and any other factors relevant to understanding the cohort of people with psychosocial disability accessing the NDIS.

Scheme supports

DRAFT RECOMMENDATION 4.1

The National Disability Insurance Agency should:

- implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review
- review its protocols relating to how phone planning is used
- provide clear, comprehensive and up to date information about how the planning process operates, what to expect during the planning process, and participants' rights and options
- ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre planning with participants.

Endorse.

These changes will improve the experience of people with psychosocial disability, allowing better communication and creating a more flexible and responsive planning process.

DRAFT RECOMMENDATION 4.2

The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.

Strongly endorse.

Advocate the introduction of both specialist psychosocial gateway for access *and* specialist planners for planning.

Boundaries and interfaces with the NDIS

DRAFT RECOMMENDATION 5.1

Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount (of \$131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach \$131 million should be made available from the National Disability Insurance Agency's program delivery budget.

The effectiveness of the ILC program in improving outcomes for people with disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five yearly review of scheme costs. The ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.

Strongly endorse, noting that:

MIFA advocates a significant increase in the amount dedicated to the ILC. See page 14.

DRAFT RECOMMENDATION 5.2

The Australian, State and Territory Governments should make public their approach to providing continuity of support and the services they intend to provide to people (including the value of supports and number of people covered), beyond supports provided through the National Disability Insurance Scheme. These arrangements for services should be reflected in the upcoming bilateral agreements for the full scheme. The National Disability Insurance Agency should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability.

Strongly endorse, noting that:

Participants in transitioning programs should not be required to test their eligibility for the NDIS. Many are patently ineligible due to the misalignment between programs set for transition into the NDIS, and forcing them to test is not only stressful for them, but administratively burdensome.

DRAFT RECOMMENDATION 5.3

Each COAG Council that has responsibility for a service area that interfaces with the National Disability Insurance Scheme (NDIS) should have a standing item on its agenda to address the provision of those services and how they interface with NDIS services. This item should cover service gaps, duplications and other boundary issues.

Through the review points of National Agreements and National Partnership Agreements under the Federal Financial Relations Intergovernmental Agreement, parties should include specific commitments and reporting obligations consistent with the National Disability Strategy. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples.

Endorse.

Provider readiness

DRAFT RECOMMENDATION 6.1

The Australian Government should:

- immediately introduce an independent price monitor to review the transitional and efficient maximum prices for scheme supports set by the National Disability Insurance Agency (NDIA)
- transfer the NDIA's power to set price caps for scheme supports to an independent price regulator by no later than 1 July 2019.

The body tasked with price regulation for scheme supports should:

- collect data on providers' characteristics and costs. This should include appropriate funding to continue the business characteristics and benchmarking study currently undertaken by National Disability Services and Curtin University
- determine transitional and efficient prices for supports at a state and territory level
- comprehensively review and publish its price model on an annual basis. This review should be transparent, have public consultation, be evidence based and evaluate the effectiveness of prices in meeting clearly defined objectives
- assess and recommend when to deregulate prices for supports, with particular regard to the type of support and region, on the basis that prices should only be regulated as narrowly, and for as short a time, as possible.

Endorse, noting that:

The complexity of providing support in the context of psychosocial disability should be reflected in pricing.

Note the following report for the PC's reference, which provides a comprehensive summary of the broader issues with pricing: Cortis, N., Macdonald, F., Davidson, B. and Bentham, E. (2017). Reasonable, necessary and valued: Pricing disability services for quality support and decent jobs. Available at:

http://apo.org.au/system/files/98111/aponid98111-354151.pdf

Workforce readiness

DRAFT RECOMMENDATION 7.1

The roles and responsibilities of different parties to develop the National Disability Insurance Scheme workforce should be clarified and made public.

- State and Territory Governments should make use of their previous experience in administering disability care and support services to play a greater role in identifying workforce gaps and remedies tailored to their jurisdiction.
- The Australian Government should retain oversight of workforce development, including how tertiary education, immigration and aged care policy interact and affect the development of the workforce. In doing so, the Australian Government should pay particular attention to immigration policy to mitigate workforce shortages over the transition period.
- The National Disability Insurance Agency should provide State and Territory Governments with data held by the Agency to enable those jurisdictions to make effective workforce development policy.
- Providers of disability supports should have access to a clear and consistent mechanism to alert those tasked with

Endorse, noting that:

The peer workforce plays a special role in community mental health, and should be nurtured. See page 14.

market development about emerging and persistent workforce	
gaps.	
DRAFT RECOMMENDATION 7.2 The National Disability Insurance Agency should publish more detailed market position statements on an annual basis. These should include information on the number of participants, committed supports, existing providers and previous actual expenditure by local government area. The Australian Government should provide funding to the Australian Bureau of Statistics to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.	Endorse, noting that: Market positions should also include information about providers, including not just the number of providers but the number of providers delivering services and the extent of services; as well as more detailed analysis of access decision-making, including characteristics of those entering the scheme and reasons for rejection. This information should be fed to PHNs to support regional service planning and gap analyses as an indicator of expressed, un-met need.
DRAFT RECOMMENDATION 7.3 The National Disability Insurance Agency's (NDIA) guidelines on paying informal carers who live at the same residence as a participant should be relaxed for core supports for the period of the National Disability Insurance Scheme (NDIS) transition. Such payments should be: • accessible under clearly defined and public guidelines, which make reference to worker shortages in the relevant market using the NDIA's information about providers and supports in the participant's region • set at a single rate determined by the NDIS price regulator in a transparent manner • reviewed by the NDIA as part of plan reviews.	No position.
Participant readiness	
DRAFT RECOMMENDATION 8.1 The National Disability Insurance Agency should implement the eMarketPlace discussed in the Integrated Market Sector and Workforce Strategy as a matter of priority.	No position.
Governance	
DRAFT RECOMMENDATION 9.1 The requirement that changes to National Disability Insurance Scheme Category A Rules have unanimous agreement from the Australian Government and all host jurisdictions should be relaxed.	No position.
DRAFT RECOMMENDATION 9.2 The Western Australian Government and Australian Government should put in place arrangements for Western Australia to transition to the National Disability Insurance	No position.

Scheme. Any decision to join the national scheme should be made public as soon as possible.	
DRAFT RECOMMENDATION 9.3 The National Disability Insurance Agency should publicly report on the number of unexpected plan reviews and reviews of decisions, review timeframes and the outcomes of reviews.	Endorse.
DRAFT RECOMMENDATION 9.4 The performance of the National Disability Insurance Scheme (NDIS) should be monitored and reported on by the National Disability Insurance Agency (NDIA) with improved and comprehensive output and outcome performance indicators that directly measure performance against the scheme's objectives. The NDIA should continue to develop and expand its performance reporting, particularly on outcomes, and Local Area Coordination and Information, Linkages and Capacity Building activities. The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with their plans and their planning experience, plans completed by phone versus face to face, and plan reviews). The Integrated NDIS Performance Reporting Framework should be regularly reviewed by the NDIA and the COAG Disability Reform Council and refined as needed.	Endorse, noting that: The outcomes for service providers should also be monitored, see page 11. The outcomes for ILC are among the most important for achieving genuine transformative cultural change, see page 14.
DRAFT RECOMMENDATION 9.5 In undertaking its role in delivering the National Disability Insurance Scheme, the National Disability Insurance Agency needs to find a better balance between participant intake, the quality of plans, participant outcomes and financial sustainability.	Endorse, noting that: The NDIS functions as an entitlements system, not a capped funding program; financial considerations should not limit this intent, which adopts the actuarial model wherein timely, fully funded supports will provide savings in time.
Funding Arrangements	
DRAFT RECOMMENDATION 10.1 At full scheme, the annual operating budget for the National Disability Insurance Agency should be set within a funding target of 7 10 per cent of package costs with the expectation that, on average, it would sit at the lower end of the band. The National Disability Insurance Agency should be required, in its annual report, to state reasons why it has not met this target in any given year.	No position.
DRAFT RECOMMENDATION 10.2 The Australian Government should reconsider the staffing cap on the National Disability Insurance Agency, given the importance of developing internal capability and expertise.	No position.

DRAFT RECOMMENDATION 10.3

In kind funding arrangements should be phased out by the end of transition and should not form part of the intergovernmental agreements for full scheme funding. Should in kind funding persist beyond transition, jurisdictions should face a financial penalty for doing so.

No position.

MIFA thanks the Productivity Commission for the opportunity to provide input into the NDIS Costs Position Paper.

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.

Appendix A: Options for achieving recovery oriented psychosocial support in the NDIS

Options for achieving recovery oriented psychosocial support in the NDIS

Supplementary submission to the Joint Standing Committee on the NDIS inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

This supplementary submission has been prepared for the Joint Committee on the National Disability Insurance Scheme in response to its question on what needs to change for the Scheme to have a recovery focus for people with psychosocial disability. We believe the issue, which is the subject of widespread stakeholder concern, has arisen in part because the Scheme was initially designed for people with physical disability, with psychosocial disability a late addition.

Our recommendations are informed by the principles in the *National Framework for Recovery-Oriented Mental Health Services*, endorsed by the Australian Health Ministers' Advisory Council in 2013. A recovery-oriented approach aligns with the objective of the NDIS to maximise independence and social and economic participation at the individual level. A recovery orientation is also consistent with the Scheme's emphasis on choice and control.

The options presented are intended to clarify the original intended cohort for the Scheme – i.e. people with the greatest need for disability support – not to expand the Scheme's reach. We do not recommend a relaxation in access criteria or their application, but instead to make improvements in order to assist the right people to access the NDIS as easily as possible.

Legislation

We recommend the following amendments to section 24 of the *National Disability Insurance Scheme Act 2013*:

- Remove references to *psychiatric condition* and replace with *psychosocial disability*. Using a validated assessment tool, a full assessment of a person's functional capacity to undertake activities of daily living can preclude the current requirement that a *psychiatric condition* be demonstrated by medical certification.
- Replace the word *permanent* with *ongoing, enduring,* or *chronic*
- Consider incorporating into 24.1 (b): the impairment or impairments are ongoing, or likely to be ongoing without the person receiving supports intended to build their capacity.

While a change to the legislation is necessary, we believe the urgent priority is to ensure the operation of the Scheme is recovery-oriented for people with psychosocial disability.

Regulation

Amendments to NDIS Rules will give the NDIA greater flexibility to implement the Scheme for people with psychosocial disability based on recovery principles. We recommend the following amendments to the Rules:

Amend the National Disability Insurance Scheme (Becoming a Participant) Rules 2016 to:

- Include the principle of recovery-oriented practice for psychosocial disability.
- Remove the requirement that psychosocial disability must be, or likely to be, permanent. (Subrule 5.1.(e) requires that a person is likely to require support under the NDIS for their lifetime, which adequately covers the longevity of the impairment.)
- Clarify that Rule 5.4 does not apply to psychosocial disability, to reflect that people with mental illness will receive ongoing clinical, medical and other treatments and psychosocial services to aid their recovery.

Rule 5.4 An impairment is, or is likely to be, permanent (see paragraph 5.1(b)) only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.

• Recognise that medical evidence obtained for the purposes of gaining the Disability Support Pension is sufficient in confirming both the medical fact of and the enduring nature of a psychosocial disability.

Amend the National Disability Insurance Scheme (Supports for Participants) Rules 2013 to:

- Recognise that a recovery-oriented approach will be taken by the NDIA in determining support needs for people with psychosocial disability.
- Require that a validated assessment tool is used for assessing reasonable and necessary supports for people with psychosocial disability, which would ensure equity for these NDIS participants while enabling the NDIS to operate according to insurance principles with timely investment to minimise lifetime costs.

Operational processes

The universal model of the NDIS is admirable. However, unique needs can and should have tailored approaches, such as that which has already occurred with early childhood. Recovery-oriented practice can be applied to the operational aspects of the Scheme for psychosocial disability.

Given the philosophical differences between the recovery-oriented assessment of and planning processes for people with psychosocial disability and those with other disabilities, the organisational structure of the NDIA should accommodate a specific psychosocial disability stream and NDIA staff (including staff involved in assessment and planning) should have expertise in psychosocial disability.

Other options for recovery-oriented practice in NDIS processes are set out below.

Assessment process

- Remove the requirement for people with psychosocial disability to produce medical
 evidence of the psychiatric condition and a medical testament to its permanence.
 This administrative practice to truncate individualised assessment of functional
 capacity is not a recovery-oriented approach to providing psychosocial supports
 services for people with mental illness.
- Adopt a validated assessment tool that is fit for purpose to assess the eligibility of people with psychosocial disability that focusses on their impairment and functional capacity to undertake activities of daily living.
- Assessment of people with psychosocial disability should be undertaken by a person
 with the right professional expertise. This can be done within the NDIA or
 outsourced, noting that the professional expertise largely exists in community based
 mental health service provider organisations and mental health professionals working
 with people with psychosocial disability.

Planning process

- Participants' plans should be oriented to capacity building supports to aid recovery, wherever possible.
- The planning process should be based on evidence of what constitutes effective and recovery-oriented packages of support for psychosocial disability.

Pricing

 Prices for psychosocial supports services should reflect the costs of a recoveryoriented services, i.e. not simply assistance with activities of daily living.

Since rollout commenced, mental health providers have repeatedly highlighted that the price of supports is set well below the hourly rate for psychosocial support work currently delivered by suitably qualified people. There is no hourly price for psychosocial support services in the NDIS Price Guide, and mental health providers have had no involvement in the process to set prices for different support types.

Background

The National Framework for Recovery-Oriented Mental Health Services was developed by the Australian Health Ministers" Advisory Council in 2013 and is formal government policy. The Framework acknowledges that "Words and language are critically important in the mental health field where discrimination, disempowerment and loss of self-esteem can cause people to battle with self-stigma". This is why the use of the term "permanent" in the NDIS legislation presents such a big barrier to the cohort for whom the Scheme is intended to support. It is why so many stakeholders have made this point in their submissions to Parliamentary inquiries, review of the NDIS legislation and to the Productivity Commission.

In 2015, reporting on its review of the *National Disability Insurance Scheme Act 2013*, Ernst and Young recommended that the government conduct another review of the Act in two to three years given that the "legislative framework will be exposed to more participants, more

locations and more sources of stress". Ernst and Young noted that the [second] review will "help government ensure that the legislative framework is 'fit for purpose' for full Scheme".

Eligibility assessment tool

In its advice for implementing the NDIS for people with mental health issues², the NDIS Independent Advisory Council found there was "no commonly accepted and used instruments for assessing functional impairments and indicating support needs related to disability due to a psychiatric condition". The Council highlighted the risk of inconsistent approaches in both eligibility and support needs being determined by the NDIA.

The issue remains unresolved and the Council has recommended, in its submission to the Parliamentary Joint Standing Committee on the NDIS, that the NDIA "invest in the development of a validated instrument for identifying an evidence-based approach to the determination of functional impairments and support needs for people with an impairment related to a psychiatric condition". It is unclear what has prevented the NDIA from: a) developing an NDIS specific tool; b) modifying the existing assessment tool for physical disability to assess psychosocial disability; or c) purchasing the licence for an existing psychosocial assessment tool.

Frank Quinlan CEO Mental Health Australia

Mental Health Australia Tony Stevenson CEO Mental illness Fellowship Australia



Liz Crowther
President
Community Mental Health Australia



 $^{^{\}rm 1}$ Ernst and Young. Independent review of the NDIS Act. December 2015. Page 3.

² Independent Advisory Council for the National Disability Insurance Scheme, IAC advice on implementing the NDIS for people with mental health issues, 2014