**Mental Health Carers Australia**

National Mental Health Carer Voice

Productivity Commission

# Response to position paper on the National Disability Insurance Scheme (NDIS) costs

A submission by Mental Health Carers Australia

July 2017

## Contents:

For further information please visit www.mentalhealthcarersaustralia.org.au or contact Jenny Branton, Executive Officer, Mental Health Carers Australia

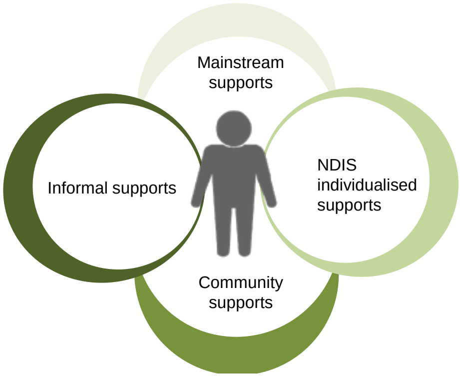
## Introduction:

Thank you for the opportunity to comment on the Productivity Commission position paper on NDIS costs. Mental Health Carers Australia (MHCA) is a member based national organisation representing people who support and/or care for a person with a mental illness. The state based member organisations have extensive connections with and understanding of families and carers of people with a mental illness.

## Support for the Commissions Position:

### Person Centred Approach:

There are many elements and recommendations within the paper that MHCA supports. The most significant of these is the identification of informal supports, including families and carers, as equal players in the support system[1]. Informal mental health carers in Australia are contributing $13.2bn annually[2] by caring for people with mental illness. Without this informal support the overall functioning and quality of life of people with a mental illness would be poorer.



Person centred approach

MHCA would encourage the commission to go further and recommend the NDIA adopt the Triangle of Care model of support. Carers are often the only constant in the mental health service consumer's journey**.** They are there when crisis occurs, when the person is well and when that person needs support with day-to-day activities. They often understand the service user's needs and condition extremely well and as such are a vital partner in care.

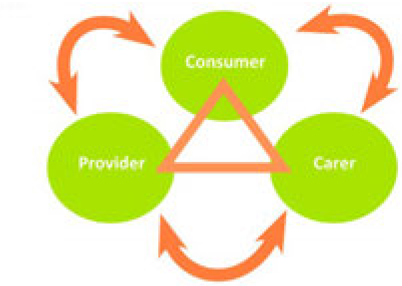


Diagram: Triangle of Care model

MHCA has, in collaboration with Mind Australia, HelpingMinds, Private Mental Health Consumer Carer Network and Mental Health Australia, developed *A Practical Guide to Working with Carers Of a Person with Mental Illness* and strongly recommends that it be used by the NDIA to improve outcomes for participants with psychosocial disability. MHCA would be happy to assist with this in any way.

### *Confidentiality and Self Determination:*

Often, when services come across the concept of the triangle of care they cite concerns about confidentiality and self-determination. The triangle of care model in no way diminished the critical principles of confidentiality and self-determination but rather it recognises people do not develop, manage or recover from mental illness in isolation and provides a way to ensure the expertise of the three partners in care, the person with the

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[1] NDIS Costs, Productivity Commission Position Paper, Overview and Recommendations
[2] The economic value of informal mental health Caring in Australia, University of Queensland 2016

mental illness, the carer and the provider are best engaged to achieve the best outcome for the person. *A Practical Guide to Working with Carers Of a Person with Mental Illness* provides the "how" to do this.

Recommendation: That the Productivity Commission recommend the NDIA implement the triangle of care model and use *A Practical Guide to Working with Carers of People with a Mental Illness* for implementation.

### Support for Other Recommendations:

Mental Health Carers Australia also supports:

- *"Greater emphasis on pre-planning, in-depth planning conversations, plan quality reporting, and more specialised training for planners"*

  For NDIS to achieve its intentions around capacity development and enhanced independence/participation for people with psychosocial disability, those people will need to work with planners who have expert knowledge on what works to build capacity in relation to their life goals and specific circumstances. There is evidence coming from NDIS participants that planners lack the expertise they need in psychosocial disability support[3] and the risk is, that without better planning, people will end up with supports that inadvertently create dependency rather than build capacity with consequent impacts on cost. In additional to this and following on from the previous point MHCA would like to emphasise families and carers should be involved in the planning process because they have valuable information that planners can use to help identify appropriate supports that will maximise capacity development for the individual and their family (i.e. sustain the caring role) and so lessen potential future increase on cost from increased support needs.

- *"Governments must set clearer boundaries at the operational level around 'who supplies what' to people with disability, and only withdraw when continuity of service is assured"*.

  Mental Health Carers Australia ardently recommends that this approach apply to supports for carers as well as participants.

- *"Some emerging shortages need to be mitigated by better price monitoring and regulation; better tailored responses to thin markets; formal and informal carers allowed to provide more paid care"*.

  MHCA recommend that the Commonwealth invests in the development of Family Peer Support networks where there are thin markets, including:

  - In rural and remote communities
  - In indigenous communities
  - For rare and uncommon diagnosis and disability
  - Where there is a miss-match between demand and supply of supports

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[3] Mind Australia project "Understanding people with psychosocial disability as choice makers in the context of the NDIS"

Peer support programs have been found to improve the well being of both carers and consumers. [4]

Randomised control trials have repeatedly demonstrated that family interventions that provide some combination of mental illness education, support, problem solving training and crisis intervention, in combination with appropriate medication, reduce one-year relapse rates from a 40 to 53 per cent range to a 2 to 23 per cent range[5].
Peer support is not intended to replace clinical programs but rather to complement and boost traditional care and provides potential for improved mental health services and programs [6]

## Psychosocial Disability Functional Assessment:

One omission in the position paper is any reference to the need to introduce a robust assessment tool of functional impairment related to psychosocial disability. There is no tool presently being used by the NDIA. The lack of this tool is at the core of the problems around psychosocial disability and the NDIS. It impacts on package size and on what can be counted as 'reasonable and necessary'. Such a tool would need some kind of standardisation against reference packages i.e. notional packages that meet particular cohort's needs that could relate to things like diagnosis, social situation and geographic location. It would also need to be capable of accommodating the individual in their family/social context.

Recommendation:
That as a matter of urgency NDIA develop and implement an effective, consistent and standardised tool to assess impairment and capacity related to psychosocial disability.

Mental Health Carers Australia is aware of work currently being undertaken to create resources to improve assessment of impairment related to psychosocial disability

MHCA is also concerned about the cost associated with obtaining information from psychiatrists, occupation therapists and other practitioners required to establish eligibility and the potential barrier this creates for people on low incomes being assessed as eligible.

"After 11 months of waiting and supplying every document they wanted, including paying $1000 for a functional assessment and other reports, I finally got an answer yesterday"

Mental Health and the NDIS Facebook page.

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[4] ARAFEMI Victoria - Centre of Excellence in Peer Support.
[5] Family Interventions for schizophrenia, Dixon and Lehman, 1995
[6] Mental Health Commission of Canada. (2013). Guidelines for the Practice and Training of Peer Support.

Recommendation:
That NDIA collect information about cost to people with a mental illness to gain reports from specialists to establish eligibility.
That the NDIA develop templates to assist specialists to provide the information they require.

## Anticipated Future Savings:

The position paper refers frequently to anticipated future savings for the scheme, to be achieved through people reducing their support needs or exiting from the scheme. It also states that *“The number of participants exiting the scheme has been lower than expected”.*

### Early Intervention:

The provision of early intervention and other support which improve people’s functional capacity and reduce their need for supports is identified in the position paper as one of the major ways to facilitate peoples’ exit from the scheme. Whilst people who have identified psychiatric conditions which are likely to be permanent is included in in the NDIS early intervention eligibility criteria, MHCA’s understanding is that early intervention strategies are generally not being included in packages for people with mental illness. There is significant evidence that people with psychosocial disability make significant gains in their capacity to engage in social and economic life if they participate in early intervention and that the improved capacity will in turn reduce their reliance on the NDIS into the future, reducing costs over time and reducing pressure on other health services[7].

It follows then, to facilitate reduced support needs and potentially exit from the scheme and therefor lower cost, early intervention should be a greater focus in packages for people with mental illness.

### Informal Supports:

Research into effective interventions highlights the importance of ensuring that families are respected and valued partners in care and feel supported to provide sustained care as needed for their family member[8].

Recommendation: That early intervention activities are investigated in the planning process and where appropriate included in packages for people with psychosocial disability and that families and informal carers be engaged in the planning and design of the interventions.

## Advocacy:

The Commission has rightly identified that many people, particularly people with mental illness struggle to understand and navigate the NDIS and these people are at risk of experiences poorer outcomes.

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[7] Mind Australia and The Centre for Mental Health, Melbourne School of Population and Global Health., Effective, evidence-based psychosocial interventions suitable for early intervention in the National Disability Insurance Scheme (NDIS): promoting psychosocial functioning and recovery.

[8] ‘Early intervention and recovery for young people with early psychosis: consensus statement’,The British Journal of Psychiatry, Bertolote J & McGorry P 2005,

*"Often these are people who cannot effectively advocate for themselves, particularly people with psychosocial disability, and those who find it difficult to navigate NDIS processes"*

*"Qualitative data suggests that those who are unable to navigate the NDIA website to find service providers, and those less able to articulate support needs, are less likely to feel that they have more choice and control."*
Mental Health Carers Australia believe that without strong formal and informal advocacy and assertive outreach the principles "*that individuals' support needs are different, and that scheme participants should be able to exercise choice and control over the services and support they receive"* underpinning the scheme, are seriously at risk.

People who are unable to navigate the system are at risk of not receiving an accurate assessment of their support needs which can result in a poor support and insufficient supports. Quality plans are critical not only for participant outcomes but for containing long-term costs of the scheme[9]. It is critical that formal and informal advocacy is available to these people.

Provision of advocacy service will reduce the likelihood that quality plans are reliant on participant's capacity to pay for advocacy. The two quotes below are from the Mental Health and the NDIS Facebook page.

*"OMG! I had a phone conference with my lawyer and advocate today. NDIA have definitely breached legislation"*

*"Really struggling atm as my plan is in limbo as supports have fallen apart. Feeling so lost and struggling"*

Families and informal carers are well placed to provide informal advocacy, they generally know the person when they are well and unwell, they often have insight into factors that impact on the person's health and capacity and what supports and interventions have worked in the past.

In addition to this formal advocacy services should be readily available and funded outside the NDIS for both carers and participants.

Recommendation:
That families and informal carers be supported to advocate for their family member or person they care for.
That funding be provides outside the NDIA for advocacy supports for carers and participants.

## Recovery Model:

MHCA agrees that in principle the "*investment approach to the NDIS and the recovery model of mental health are both about building capacity, and appear to be well aligned"*, however, is concerned that assessment for eligibility, how permanence is determined and that the pricing structure does not accommodate the forms of support many people need to build capacity will mean people with mental illness will not have access to recovery based interventions.

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[9] Productivity Commission, NDIS Costs, Position Paper, Overview and Recommendations.

Recommendation:
That NDIA review assessment and pricing structures to identify where they might impinge on access to capacity building supports by people with mental illness and instigate changes to those structures to improve access.
That psychotic disorders including schizophrenia, bi polar disorder and personality disorder be added to List B

## Information Requests:

### Scheme Supports 4.1

*Is better legislative direction about what is reasonable and necessary required?*

Mental Health Carers Australia supports ongoing review of what deemed reasonable and necessary in order to ensure excellent psychosocial disability supports are in place. This will increase costs in the short term but should offset them in the long run. Without those excellent supports the costs to the public purse are likely to increase over the long term, but not necessarily to the Commonwealth government but more likely to fall on state systems like health, criminal justice and homelessness.

Recommendation:
Rather than changing legislation use regulations, rules and guidelines to modify what is determined as reasonable and necessary.
Aim to retain a level of flexibility about what is reasonable and necessary in order to maximise participant's choice and control.

### Scheme Supports 4.2

*Should the National Disability Insurance Agency have the ability to delegate plan approval functions to Local Area Coordinators?*

Yes for plans within allocation, however there needs solid appeal processes for people who feel the plans do not meet their needs.

### Workforce Readiness 7.1

*What is the best way for governments and the National Disability Insurance Agency to work together to develop a holistic workforce strategy to meet the workforce needs of the National Disability Insurance Scheme*

Invest in the development and implementation of a Family Peer Worker model. Mental Health Carers Tasmania are currently working on a project that could inform this.

Use the expertise of carers and mental health consumers to develop workforce training materials.

Mental Health Carers Australia supports the Commission's proposal to *"Temporarily relax the restrictions on NDIA payments to informal carers to encourage them to provide more care over the transition period".* Were this to occur NDIA planners would need to ensure carers are willing to undertake the work and do not feel pressured into it, participants are happy with the arrangement and carers understand what impact the work might have on other payments they receive.

## Workforce Readiness 7.2

*How has the introduction of the National Disability Insurance Scheme affected the supply and demand for respite services?*

Almost 40% of primary mental health carers provide 40 or more hours of care per week[10]. Mental health carers face mental ill health as a direct consequence of their caring role and experience higher rates of mental ill health than the general population[11].

Mental Health Carers Australia is very concerned that

- the introduction of the NDIS and the associated transition of considerable carer support and respite funding into the NDIS
- the requirement for carer supports to be part of the recipients package
- the apparent lack of understanding of the diverse nature of potential supports a carer might need (beyond the concept of respite)
- the lack of independent assessment of carer support needs

puts carers at risk of not receiving the supports they need to continue to participate in a full range of activities including the workforce and to continue in their caring role.

> Help line caller on 16/01/2017 – *"Again carer is left without support while they are waiting for NDIS plan approval - Respite from Disability Trust has run out. Sister has Bipolar disorder and is staying with family until the NDIS approves the package of support. The sister with bipolar has been violent with family members. Caller seeking some resources to find emergency respite for sister until NDIS is approved."*

Without sufficient supports it is likely more carers will become unwell themselves, putting added cost on the health system and not be able to continue in their caring role, resulting in people with psychosocial disability needing formal supports.

> Recommendation:
> That provision of carer support services and the associated funding sit outside the NDIS. That the provision of carer supports be determined by an assessment of the carers support needs

## Participant Readiness 8.2

*Is there scope for Disability Support Organisations and private intermediaries to play a greater role in supporting participants?*

Yes, particularly in the areas of care planning, carer and participant advocacy and care coordination. This would be one strategy to deal with workforce shortages. It would

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[10] Mind Australian and the University of Queensland, The economic value of informal mental health caring in Australia, 2017

[11] Psychological Distress in Carers of People with Mental Disorders, Aadil Jan Shah, Ovais Wadoo and Javed Latoo, 2010

however, need a robust system of safeguards to ensure participants maintain choice and control and that the intermediaries do not simply become another layer to be navigated in an already complex system.

## Conclusion:

Mental Health Carers Australia and it's member organisations are confident that by working with mental health carers, consumers, service providers, NDIA and government, the experience of carers can be improved. Improving the capacity of carers in tern improves the experience and outcomes for people with mental illness. MHCA is grateful for the opportunity to provide this submission and is keen to continue work to ensure the best possible outcome for people with mental illness, their carers and their families and is happy to support the process in any way possible. Should you want any further information or if MHCA can assist in any way please contact Jenny Branton, Executive Officer