



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

March 2017

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

For information contact:

Ms Ara Cresswell
Chief Executive Officer
Carers Australia
Unit 1, 16 Napier Close
DEAKIN ACT 2600
Telephone: 02 6122 9900
Facsimile: 02 6122 9999
Email: acresswell@carersaustralia.com.au
Website: www.carersaustralia.com.au

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EXECUTIVE SUMMARY

Carers Australia welcomes the opportunity to make a submission on *The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*.

While the terms of reference for the inquiry are focused on people with psychosocial disability, we believe this is an important opportunity to identify how the NDIS has impacted their carers.

With respect to issues more closely related to those they care for, we endorse the comments and recommendations raised in the submission of Mental Health Australia (MHA) with whom we work closely.

Carers Australia is a strong supporter of the NDIS and indeed, through the National Disability and Carer Alliance (NDCA), campaigned vigorously for its implementation.

However a number of aspects of NDIS implementation have been disappointing from the carer perspective. Not only does the NDIS not provide supports to carers in their own right to assist their wellbeing and sustain them in their caring role but also, funding from a dedicated and highly successful carer support program for mental health carers - which was established prior to the NDIS - is being transferred to the NDIS.

The transfer of this funding astonishingly is ill-targeted.

The Mental Health Respite: Carer Support program (MHR:CS) is the second largest carer support program in the suite of carer programs delivered by the Department of Social Services. It supported 40,644 carers in 2014-15. The program not only funds respite, but also a range of other supports directed to the special needs of mental health carers. In 2015-16 \$63.974 million was allocated to MHR:CS. This funding is incrementally being transitioned into the NDIS as it rolls out. Upon full rollout in 2019-20 all funds will have transitioned.

Among carers who need support services in their own right, mental health carers have a particularly strong need for support. The emotional stress of caring for someone with a mental health disorder and challenging behaviours, is incredibly debilitating. It is also the case that both eligibility for NDIS support and the availability of services for the people they care for is a particularly complex and uncertain element of NDIS implementation – as the Mental Health Australia submission makes abundantly clear.

The upshot is that these mental health carers are enduring a double-whammy. The people they care for are not benefitting from the NDIS to the extent they should be

and continue to rely heavily on family and friend carers for support, and at the same time these carers are losing access to a highly successful and valued carer support service.

The body of this submission provides evidence to support the propositions outlined in this Executive Summary.

Recommendation:

- Existing government funding dedicated to assisting mental health carers to meet their own needs should cease to be transferred to the NDIS immediately. Such funding should be maintained within the current carer support suite of programs offered through DSS and transferred in full to the proposed Integrated Carer Support Services program if that program is implemented
- Eligibility to access MHR:CS funded services or any program which might replace it through the implementation of an Integrated Carer Support Services program should not be predicated on the access of the person or persons being cared for to the NDIS either as a recipient of a support package or through the Information, Referral and Linkages (ILC) program.

About mental health family and friend carers

- Based on analysis of the Australian Bureau of Statistics' (ABS) 2015 Survey of Disability, Ageing and Carers (SDAC), there were 194,000 primary carers caring for someone who had a psychosocial condition as their main disabling condition.¹ This represents about a quarter of the primary carer population.²
- Fifty percent of respondents to the survey reported providing 40 hours or more of care per week, 15% provided between 20 and 39 hours of care, and 28% provided less than 20 hours of care.
- In a 2012 survey of mental health carers, 71% of respondents reported a deterioration of their health in the previous 12 months as a direct result of caring for someone with a mental illness.³

Support services for mental health carers

The importance of carer support services- such as respite from caring, counselling, peer support and education - is well established.

The 2015 Survey of Ageing, Disability and Carers (SDAC) echoed the findings of the ABS's earlier SDAC surveys. Analysis of carers' use of respite services identified against the primary clinical condition of the care recipient shows that carers of people with mental and behavioural disorders are most likely to have used respite.

In recognition of the special need for support for mental health carers, the Australian government introduced a dedicated support and service program for them in the 2011-2012 Budget, which allocated \$54.3 million over five years to expand mental health respite and carer support services. This funding was increased over time due to demand and the evaluation of the effectiveness of the program.

The Mental Health Respite: Carers Support (MHR:CS) program provides relief from the caring role through in-home or out-of-home respite or social and recreational activities, counselling, practical assistance, social inclusion activities, case management; and education, information and access. It also funds community mental health promotion. The highest priority is given to carers without access to similar respite or carer supports through other government funded services. It also

¹ Includes mental retardation/intellectual disability, autism and dementia

² Analysis of the Australian Bureau of Statistics, 2015 Survey of Ageing, Disability and Carers

³ Mental Health Council of Australia, Recognition and Respect; Mental Health Carers Report 2012, p.18

recognises that carers of people with psychosocial disability frequently suffer very high levels of stress, particularly those who are caring for people with very challenging behaviours. In 2014-15 this program assisted 40,644 carers. ⁴

A 2015 Carers NSW Mental Health Respite: Carer Support Evaluation, which included a carer survey, found that 95.6% of carers who had participated in the MHR:CS program reported either slight or significant improvements in their caring roles. The nature of these improvements included feeling more in control, being more able to cope, being more able to set and achieve goals, feeling less isolated, feeling more valued and recognised, improved relationships with family, feeling more hopeful and feeling less stress.⁵

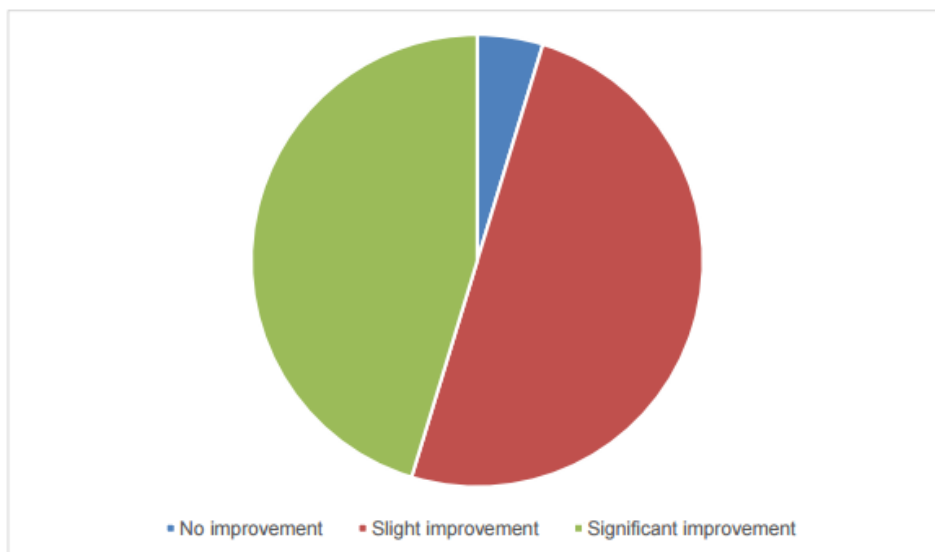


Figure 6. Extent of improvement in caring roles as a result of the MHR: CS program

Loss of mental health carer supports and supports for those they care for under the NDIS

Given the high demand for this kind of support for mental health carers it seems particularly paradoxical and unfair that this particular source of carer funding has been earmarked for gradual transition into the NDIS as it is rolled out nationally, with all funding expected to transition by 2019-20. It is important to note that this source of funding will not only be lost to mental health carers of people who are eligible for NDIS packages, but also to those caring for someone who is not eligible for the NDIS.

⁴ Department of Social Services, *Designing the new integrated carer support service, Discussion Paper 1, Appendix B, May 2016*

⁵ Carers NSW, *Mental Health Respite: Carer Support Evaluation 2015*, pp.9-11

Not only is eligibility for NDIS packages for people with mental health disorders a particularly fraught area, but the NDIS does not provide support services to carers in their own right. As the *Plain English Guide to Supports for Families and Carers under the NDIS* puts it, if carers and families have need of supports and services in their own right they are directed to find them through “other government programs”.⁶

CASE STUDY: Carer Support (MHR:CS)

A mother cares for her 16 year old daughter, who has a treatment resistant mood disorder, ongoing suicidality, and an Autism Spectrum disorder. At the time of application to the NDIS, the daughter had been an inpatient at an adolescent mental health unit for the previous five months, and was looking to be discharged from the unit gradually, requiring a lot of support.

Prior to her becoming an NDIS participant, the Mental Health Respite: Carer Support program had funded the daughter’s recreational activities and interests; however most funding was used to provide respite and recreation for the wellbeing of both the mother and the daughter’s sister. At the NDIS planning in meeting in 2015 (at which an MHR:CS staff member was present), the NDIS planner noted such services will not be funded by the NDIS, and expressed concern about how the mother and daughter’s sister will maintain their caring role.

Mental Health Australia and Carers Australia, Mental Health Carers and the National Disability Insurance Scheme, Issues paper – January 2016

The National Institute of Labour Studies (NILS) recently released an intermediate report on the independent evaluation of the trial of the National Disability Insurance Scheme.⁷ It provides the first synthesis of the evidence collected between May 2013 and mid-2016 from all different sources and methodologies of the NDIS evaluation. While the publicly available report doesn’t distinguish between mental health carers and other carers, key carer feedback includes the following:

- Carers continue to provide the most care to NDIS participants (page xiv)
- Both the quantitative and qualitative data indicate that many family members and/or carers of NDIS participants are unable to take adequate breaks from providing support and they cannot access carer support in a consistent manner. (page xiv)

⁶ <https://www.ndis.gov.au/families-carers/information-families-and-carers.html>

⁷ National Institute of Labour Studies (NILS), Evaluation of the NDIS, Intermediate Report, September 2016.

- The qualitative evidence also suggests that support for carers (within and outside of the NDIS) has diminished since the NDIS roll-out. (page 19)

The evaluation also found that in many areas NDIS participants with mental health conditions were not achieving the benefits achieved by other participants, which also impacts on their carers' capacity to benefit through the NDIS. In particular:

- Both the qualitative and quantitative data indicate that people with mental health and psychosocial disability are more likely to report less choice and control over supports since becoming NDIS participants (page xiii).
- The quantitative data indicates that those who report that they are worse off in terms of their choice and control over their supports are more likely to have experienced a decrease rather than an increase in the number of supports they receive since becoming NDIS participants. In addition, those who report that they have funding for supports which, however, they cannot access, have lower levels of satisfaction with the overall quality of their supports (page xiii).
- While many NDIS participants are now able to take part in activities independently (i.e. without the support of a family member) that had previously been inaccessible, such opportunities are limited in the case of NDIS participants with mental health problems, intellectual disabilities, or with Autism Spectrum Disorder (page xvi).

In short, mental health carers are losing out in two ways: not only are they losing access to their own support services as a result of the NDIS, but the NDIS is not yet providing the level of support for people with mental health disorders and psychosocial disability that it does for many other participants.

Nor do we currently have confidence that the Information, Referral and Linkages (ILC) program will be able to provide adequate support to people with a mental health condition who are ineligible for an NDIS package, let alone their carers who will be among the losers with the transfer of MHR:CS funding,

As noted in Mental Health Australia's submission: "The Information, Linkages and Capacity Building (ILC) initiative is not yet filling the gaps in services created by NDIS transition, and is unlikely to do so without substantial additional investment."⁸

Carers, and our network of associations, have reported that Commonwealth, State and Territory funded services for people with disability who do not have an NDIS plan are rapidly disappearing from the service landscape; this includes the closure of mental health services and mental health carer respite services. VICSERV in its submission

⁸ Mental Health Australia (MHA), *Submission to the Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, February 2017

to this Inquiry also points to concerns about the level of funding being provided under the ILC framework and its limitations for meeting the needs of people with mental illness who are ineligible for NDIS supports, their families and carers. It notes in particular that:

“In Victoria, through the bilateral agreement with the Commonwealth Government, the Victorian Government has committed the majority of its mental health services funds to the NDIS (redirected from the Mental Health Community Support Services funds), leaving the NDIS as the only option for most people with mental health issues who require psychosocial support in Victoria.”⁹

On our understanding, the same outcomes are occurring in many other states and territories. Mental Health Australia in its submission to the Inquiry also makes the point that:

“There is a major risk of widening gaps in access to services for people who are not eligible for the NDIS, due to the winding down of government programs that currently deliver psychosocial services.”¹⁰

⁹ Psychiatric Disability Services of Victoria (VICSERV), *Submission to the Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to mental health condition*, February 2017, pages 3-4

¹⁰ Mental Health Australia (MHA), *Submission to the Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, February 2017