



MHCN mental health carers nsw

Mental Health Carers NSW Response to the Supplementary Questions by the Parliamentary Inquiry into the Implementation of the National Disability Insurance Scheme and the Provision of Disability Services in NSW.

Thank you for the opportunity to provide additional feedback to the parliamentary inquiry on 'The Implementation of the National Disability Insurance Scheme and the Provision of Disability Services in NSW'. The following correspondence responds to the supplementary questions following the hearing on October 2.

Are your members accessing the 90 days of respite that is available from the NSW Government?

Mental Health Carers NSW (MHCN) is not aware of a respite program provided directly by the NSW government which provides up to 90 days of care. MHCN may be able to provide further comment on this matter, if clarification as to the name of the respite program is provided. Based on the information received, we have been led to understand that this question refers to pg 75 of the transcript for the October 2 hearing. MHCN is of the impression that Mr. Coutts-Trotter referred to the NDIS support 'short term accommodation' as opposed to a respite program offered by the NSW government which provides 90 days of care. The NDIA provides three types of accommodation support; 'short term accommodation' and 'supported independent living' and 'supported disability accommodation'. 'Short term accommodation' is intended to provide temporary accommodation separate to participants usual arrangements. Generally, the NDIA will incorporate up to 90 days accommodation into participants plans before it is considered more appropriate to explore other more permanent supports such as 'supported disability accommodation' and 'supported independent living'.

The limited availability of temporary accommodation via the NDIS can be problematic where families require additional days of temporary accommodation in order for the family to be able to live together. In the case of families caring for a child with a disability, the result maybe that they are forced to relinquish care their child in order to ensure access to appropriate supports. As far as MHCN is aware, the only form of 'respite' provided through FACs to families of children with a disability is temporary out of home care. Based on the evidence provided by Mr Coutts-Trotter, FACs has engaged in negotiations with the NDIA to facilitate and advocate for changes to planning decisions in cases where children require additional accommodation support. Although, MHCN supports the efforts of the NSW government to promote flexibility around the period of temporary accommodation provided to NDIS participants, this does not address the need for carer respite programs in NSW.

Carer Respite and the NDIS

As outlined in our submission, the supports provided by the NDIS, such as temporary accommodation and day time activities for participants, differs to respite in the following ways;

- ***The term ‘respite’ is not used by the NDIA to describe the supports funded through the NDIS.*** The term ‘respite’ implies direct benefit to the carer, whereas the NDIS is designed with the express intention of directly supporting the participant and their choice and control over how. The scheme does not consider indirect benefits to others of supporting participants, (and carer respite has been falsely classified as only this).
- ***The NDIS does not incorporate a formal process to assess carers needs whereas respite supports consider both carer and caree needs in the assessment process.*** The feedback that MHCN has received from mental health carers indicates that there is significant variability as to how NDIA staff include family and carers during assessment, planning and review processes. It is evident from feedback that, NDIA staff do not routinely seek the views of carers nor seek to identify carers needs in addition to participants needs. The result is that the NDIA relies the information provided by the participant to determine the level of support required. This often provides an incomplete picture of the family situation, especially in the case where due to cognitive impairment the participant lacks insight into their families situation or caring role.
- ***The NDIA bases the decision to fund supports solely on participant need whereas the eligibility criteria for respite supports is based on the needs of both carer and caree.*** Carer supports will only be funded when it is demonstrated that the support will improve the sustainability of the caring role or build the capacity of family or carers to provide care to the participant. The result is that, even where carer’s needs are understood during planning processes, there is no guarantee that support for carers will be incorporated in the NDIS plan.
- ***The assumption that an NDIS package meets the needs of carers by reducing the level of care that is required is false. By contrast, respite services incorporate carer focused outcomes into the framework for service delivery.*** The supports provided in an NDIS package may incidentally have a positive ‘flow on effect’ to carers. However, MHCN has observed that in some cases the hours of care provided by carers has increased once the participant receives an NDIS package owing to the time required to implement the plan and coordinate supports. The NDIS is not appropriate as the sole avenue by which carers can access support due to the participant focused nature of the scheme. Carers have a unique set of needs which differ to and sometimes conflict with the needs of the person they care for. Supports which have a positive ‘flow on effect’ to carers differ to carer services which are designed to meet carer’s needs regardless of whether they align with the needs of the person they care for.
- ***The NDIS participant determines how and when the supports in their package are used whereas the decision to use respite supports is negotiated between both carer and caree.*** The result is that there is no guarantee that carers will be able to access NDIS supports when they need it in a timely manner. This is problematic where participant and carer disagree on the type of support required. A number of carers have reported that they are unable to access crucial supports as the person they care for lacks an understanding of their carers needs due to mental ill health or cognitive impairment.

What respites services should be offered to carers (this may be services that were previously offered, before the NDIS)?

In order to address the current gaps in service provision and complement the type of supports provided by the NDIS the NSW government should consider funding respite programs that;

- Base the eligibility criteria for the program on carer need
- Incorporate carer focused outcomes into the design and evaluation of the service
- Provide services to both carers of NDIS participants and non-NDIS participants
- Provide both emergency and planned respite services in a timely manner
- Provide specialised supports to diverse groups of carers including mental health respite
- Ensure coverage in regional, rural and remote areas

Regardless of whether services which were previously provided before the transition to the NDIS are replicated or new programs are developed, the NSW government should address the gap in service provision which has been created by the closure of ADHC in combination with reduced funding to Commonwealth Respite Services. As outlined in our submission, commonwealth services were previously funded through the Department of Social Services include; Mental Health Carer Respite Support and Young Carer Respite. These services catered to cohorts of carers who experience numerous access barriers to the NDIS. Furthermore, the availability of places for carers seeking to access the DSS funded Commonwealth Respite and Carelink Centre services has decreased. Carers of NDIS participants are ineligible for Commonwealth Respite and Carelink Centres which leaves them with no alternative avenues to access respite services where an appropriate level of support cannot be provided by the NDIS.

MHCN is particularly concerned by the closure of the Mental Health Carer Respite program. This is the only program which is dedicated to ensuring that mental health carers have access to the specialised respite services required by this cohort. Mainstream respite services are often unable to provide the specialized type of support required by people with complex needs related to mental ill health and as a result access to respite is limited for this cohort. The stigma associated with mental illness presents a significant barrier to access mainstream supports for mental health carers. It is not uncommon for mental health carers to indicate that due to stigma they feel uncomfortable accessing mainstream supports. The eligibility criteria for the NDIS requires proof of permanency of disability. The result is that a large portion of people who have significant support needs due to severe mental ill health are ineligible for the NDIS. MHCN has heard numerous examples where mental health carers are unable to be access support through the NDIS and specialised mental health respite services are unavailable elsewhere. The NSW government should consider funding specialised mental health respite services in order to address this gap.

Are you aware of the contracting of the NDIA that commenced in early July that reportedly requires nine providers (Marymead, Northcote, the Australian Foundation for Disability, Life Without Barriers, Uniting and Live Better) to act as a provider of last resort?

The NDIA has committed to developing a maintaining critical supports framework which is intended to ensure that NDIS participants have access to critical supports in the incident of market failure. In the government response to the report of the joint standing committee into the NDIS which was released in February 2018, it was stated that the NDIA was committed to publicly publishing the ‘maintaining critical supports’ framework by mid 2018. At present the framework is yet to publicly released and there is a lack of clarity as to the type and level of support that will be provided in incidents of market failure. The eligibility criteria for accessing these services and the extent to which this framework will provide the type of holistic and specialised support required by people with complex needs is also unclear. MHCN is concerned that the language of ‘critical support’ indicates that

the framework will only apply to a small number of supports which are considered essential as opposed to the entirety of the supports provided in participant plans. Furthermore, it may be the case that in incidences where these supports are unavailable a bare minimum of essential supports will be provided.

Yours in advocacy,

Johnathan Harms
CEO Mental Health Carers NSW Inc.