Mental Health Carers NSW Inc.

Submission to Joint Standing Committee on the National Disability Insurance Scheme

Parliament of Australia, Canberra ACT

Review of NDIS participant experience in rural, regional and remote Australia

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Submission prepared by:

Jonathan Harms, CEO, Mental Health Carers NSW, Jonathan.Harms@mentalhealthcarersnsw.org
Prasheela Karan, Policy Officer, Mental Health Carers NSW, Prasheela.Karan@mentalhealthcarersnsw.org
Richard Baldwin, Senior Policy Officer, Mental Health Carers NSW, Richard.Baldwin@mentalhealthcarersnsw.org

mentalhealthcarersnsw.org
Suite 2.03, Level 2, 3 Spring St, Sydney NSW 2000.

02 9332 0777

About Mental Health Carers NSW (MHCN)

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience mental illness in NSW. It is a community-based, non-government organisation that provides systemic advocacy, capacity development and education for the carers, family, friends and kin of those experiencing mental illness across NSW. It has also recently been funded under the Disability Advocacy Futures program to provide systemic advocacy on behalf of those who experience psychosocial disability.

There are currently 2.7 million unpaid carers in Australia, 39% of whom provide more than 40 hours of care per week. Due to the demands of their full-time caring role, carers are at a high risk for developing mental health issues. We work to ensure the voices of mental health carers in NSW and the people they love and support are represented and heard in policy and service reform processes to increase the willingness of the community to ensure their rights are upheld, (which requires services to realise them to be *funded*). We endeavour to empower mental health carers and the people with experience of serious and persistent mental distress they care for to become champions for mental health reform and advocacy.

This submission provides MHCN's views on the needs of people with lived or living experience of serious and persistent mental distress (consumers) who use the NDIS and their carers living in remote, rural and regional areas of NSW.

Executive Summary

Consumers and carers in regional, rural, and remote areas of Australia are forced to contend with inadequate markets of disability service providers resulting in a thin supply of services and high levels of unmet needs. Issues with inconsistent information and lack of communication, as well as fragmented services and limitations in the workforce are regularly reported and erode the faith of families in services to responsively meet needs.

We conducted a survey with mental health carers supporting an NDIS participant living in remote, rural and regional areas in NSW. In total, 14 carers responded to the survey. The survey responses, along with other reports, affirm the difficulties experienced in receiving access to psychosocial disability supports. There was a specific concern that the NDIS does not adequately support people with a mental health issue.

We reiterate recommendations made in our submission to the review of the NDIS in 2023. These recommendations are:

1. State governments should be funded to maintain an independent, peer delivered ‘service navigation and case coordination’ support service, to assist those people who require it to manage their packages.
2. There needs to be a more general NDIS market review of what can efficiently be provided by private operators or community managed organisations and what needs to be delivered as a federal government funded and state government delivered monopoly in each jurisdiction in order for it to be delivered on a cost-effective basis.
3. There needs to be a Bill of Human Rights which mandates that people must get access to certain basic rights and supports and allows government to be sued for failure.

Scope of this Submission

This submission addresses the following terms of reference as published by the Joint Standing Committee on the NDIS:

a. the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;

b. the availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;

c. participants’ choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services

Survey Results

Major challenges exist in accessing services in regional, rural, and remote areas. Reports by carers confirm that there are unmet needs because of difficulties in accessing the NDIS, limited and fragmented services, lack of understanding of psychosocial disability, and severe lack of support with navigation of the scheme.

(1) Application process impacted by poor communication

There were mixed experiences in relation to the application process. While there were reports that the application process was “fairly straightforward”, carers also responded that poor communication and inconsistent information led to a difficult and stressful application process.

Furthermore, there was evidence that not all supports were being funded, because not all disabilities were included by the mental health team in their application:

> *“The mental health team submitted the application whilst he was [in a] mental health unit but they never put down any of his physical disabilities so we are having issues adding these to the plan for the support and modifications that are required for him. We have tried once for it to be reviewed but it was knocked by not enough evidence when he receives a disabilities pension for his physical disabilities. His health especially balance is getting worse with increased falls”.*

Carers reported difficulties through the application process because of poor communication. Carers described the process as being “Difficult. Access and information were “in short, convoluted, and stressful”, “Nightmare”, and “Slow”.

A comment by one carer shows the lack of communication between services:

> *“There is no consistency across information!! Have you ever tried making an enquiry to the ndis? If you - * call the call centre OR * speak with someone at the local ndis / centrelik office OR * speak with an LAC OR *speak with a Support Coordinator you will receive 4 different answers / replies (if you are lucky to have someone with an inkling of what you are enquiring about)!! AND you are usually given the run around i.e.: Call Centre will say contact your local office, local office will say contact your LAC, LAC will say contact your SC, SC heads are tied as needs to go through LAC or ndia planner. It's a joke!!”*

These results highlight some of the burdens that carers encounter through the application process, particularly because of poor communication and lack of supports with navigating the NDIS scheme from the initial stages.

(2) Inadequate plan design process

Few carers were satisfied with the plan design process. The process was described as “*poor*’, “*complicated*”, “*overwhelming, confusing and stressful*”. There was a sense that staff had a lack of understanding of what was required through the plan design process.

(3) Mixed satisfaction with plan funding received

Responses by participants were mixed, with approximately 50% indicating satisfaction with funding received. However, there was also frustration reported in advocating for needs being met and understood. Furthermore, responses suggested that participants were not provided sufficient explanation around funding for plans and that funding was insufficient to meet needs.

The impact of inadequate knowledge on the fluctuating nature of illness associated with psychosocial disability or mental health issues was evident:

> *"Not all workers in the NDIS (or LACs) understand the complexities of mental health and what can be the episodic nature of mental illness. Flexibility is key - this aspect can be overlooked when working with providers as well. There are times where lots of support is required and then other times where the participant may not want/need as much support so will not use their funds. However, if funding is cut to their package, when there is an inevitable crisis there is not sufficient funding available for the additional support required at this time".*

Indeed, there were reports that it was difficult for NDIS to understand the needs of the person being cared for, as well as a failure to listen to where funds should be provided.

(4) Mixed experiences with plan implementation

Approximately one third of respondents were satisfied with plan implementation. Responses indicated that carers often had to provide support to ensure needs were being met. A lack of services, and delays were identified as negatively impacting plan implementation. A further issue reported was the change in NDIS rules, which affected achievement of goals set out in the plan for the person receiving support.

(5) Lack of consistency with plan reviews

There was significant variability in plan reviews, with respondents being generally dissatisfied. Issues were wide-ranging, from being "*non existent*", to "*timely and effective*". There was a major concern about the lack of adequately trained staff, services based in metropolitan areas that did not understand the challenges in rural areas and lack of acknowledgement of specific conditions requiring supports.

(6) Limited services and unmet needs

About 50% of carers were either satisfied or very satisfied that the person they were supporting had sufficient **choice and control** over NDIS services and supports. However, about 50% of survey respondents were either dissatisfied or very dissatisfied that the person they were supporting had sufficient **access** to the services for which their plan had approved funding. About one third of respondents were either satisfied and very satisfied.

Responses highlighted long waiting lists, including for speech therapists and psychiatrists and a need to travel for hours to access services. A further issue was that health professionals had limited experience with particular disabilities, and support workers having only limited training. One carer stated,

> "*Look at individual participants more and stop grouping all diagnosed together e.g., Autism, everyone is different and so are their needs*".

Limitations in the capacity of services to support persons experiencing mental health illness and problems was commonly reported by carers. For example, one carer stated,

> *"NDIS is a good concept however clients in regional areas with chronic mental illness are not catered for I believe!".*

In addition, knowledge about mental health and psychosocial disability was reported as being inadequate, with one carer stating:

> *"Yes more understanding should be shown when NDIS are dealing with challenging mental health people - in my experience the NDIS showed no knowledge at all about mental health".*

Furthermore, there were significant concerns about the availability of qualified, skilled, and experienced NDIS supports, including for psychosocial supports and recovery coaches. The need for monitoring and meeting professional development requirements was also highlighted.

The lack of appropriate and adequate services was reported to result in rehospitalisation, and NDIS funds being largely unused because of NDIS support workers needing to be dismissed, with family and friends stepping in to provide support. Responses indicated there was a significant variability in the standard of services provided, resulting in a high demand for specific services. As one carer stated,

> *"At first, we struggled to find good service providers. Now we are extremely happy with services provided".*

Altogether these reports affirm what has already been reported at length, that regional, remote, and rural areas are severely impacted by a lack of available services. They also highlight significant issues with quality of services, and lack of capacity to provide sufficient supports particularly for persons impacted by psychosocial disability.

Inappropriate Structures Underpinning the NDIS

Carers have reported significant and wide-ranging obstacles to obtaining supports for persons affected by psychosocial disability. There is a need to critically review arrangements between federal and state governments in the provision of supports, address fragmentation of services and ensure workforce training. Furthermore, addressing complex health needs via a scheme set up as a market, such as the NDIS, is inappropriate and has led to high levels of unmet needs, particularly in regard to psychosocial and intellectual disability.

We have previously argued that a review needs to be undertaken of what can be provided by private operators or community managed organisations and what needs to be delivered as federal government funded and state government delivered. In regional and remote areas, even when funds are provided, adequate supports might not be available. Worse, services to address the needs of 'high risk' clients may not exist, as we stated in our previous submission:

> *there are many needs relating to disordered behaviour and 'high risk' clients that non-government organisations or services will always struggle to be able to provide due to the liability risk and difficulties in attracting and retaining sufficiently expert staff in roles long enough for them to become sufficiently expert to undertake their roles.*

Because of the lack of specialist supports and teams, we argue, as in our previous submission, that unspent funds should be a KPI for the NDIA and should trigger a review on how the person can receive the supports when they are struggling to find a provider. Furthermore, choice and control should be promoted through accessing experts to assist with supported decision making.

We have also noted in our previous submission on the NDIS that the system of assessment, and the need to litigate "reasonable and necessary" with the NDIA is inappropriate for people with psychosocial disability. The experience of distress experienced because of psychosocial disability can have many different causes and impacts, and be associated with fluctuations in health and wellbeing. Consequently, a flexible approach is needed, including a level of freedom that would allow for determining types of needed supports.

Provide Service Navigation and Case Coordination Support

Because of these gaps, it is left to families and carers to provide the best support they can, often stepping in, including to ensure plan implementation. Targeted supports for carers are lacking and consequently, there is a failure to effectively address the difficulties experienced by carers. This has resulted in carers experiencing burnout and poor wellbeing because of their caring role, in which they face the need to independently navigate complex schemes and services.

As the results of this survey show, and in countless interactions with carers through various forums held by MHCN, navigating the mental health sector is terribly complex and frustrating. We have previously argued that peer services can effectively support families and carers, particularly as peer workers have firsthand experience navigating systems. In this regard, it is critical that:

> *state governments should be funded to maintain an independent, peer delivered 'service navigation and case coordination' support service.*

This service can hugely benefit families through all stages of the scheme, including in the management of their package, should they require it. We have also advocated that such a service would support better coordination between sectors and state and federal funded services, as well as monitoring of services, providers, and identification of unmet needs.

Recommendations

We reiterate the following recommendations as a matter of urgency:

1. There needs to be a more general NDIS market review of what can efficiently be provided by private operators or community managed organisations and what needs to be delivered as a federal government funded and state government delivered monopoly in each jurisdiction in order for it to be delivered on a cost-effective basis.
2. State governments should be funded to maintain an independent, peer delivered 'service navigation and case coordination' support service, to assist those people who require it to manage their packages.
3. There needs to be a Bill of Human Rights which mandates that people must get access to certain basic rights and supports and allows government to be sued for failure.