



Submission from the NSW Carers Advisory Council

The NSW Carers Advisory Council writes to you in regards to the Terms of Reference for the Parliamentary inquiry into the current Scheme implementation and forecasting for the NDIS.

The Council provides advice to the NSW Government on legislation, policy and other matters relating to carers. For more information about the Council and its members, the majority of whom are carers, please visit the Council website:

<https://www.facs.nsw.gov.au/inclusion/advisory-councils/carers>

Following are the Council responses to the Terms of Reference.

Term of Reference	Comment
<p>a. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:</p> <p>i. the availability of support outside the NDIS for people with disability (e.g. community-based or 'Tier 2' supports), and</p>	<p>The "Carers Missing Out" report (https://www.facs.nsw.gov.au/inclusion/advisory-councils/carers/chapters/adhc_publications) highlights significant issues relating to the availability of support outside the NDIS in NSW including the following.</p> <ul style="list-style-type: none"> *Significant changes to the service system which occurred concurrently with the introduction of the NDIS have had a negative impact on people with a disability who are ineligible for the NDIS. For example, the HACC Program was transferred to the Commonwealth, with access to services typically funded through the HACC program such as domestic assistance and therapy services, no longer available to those not accessing the NDIS. * Nearly 74% of people with a disability who need assistance to perform daily activities in NSW do not have access to an NDIS package. Many do not receive any formal supports and must rely on their carers to provide the essential support they need. More than 120,000 people with disability in NSW report a need for more formal assistance. * Those particularly at risk of inadequate support are: <ul style="list-style-type: none"> *People with mild to moderate disability *People with chronic illness resulting in significant functional limitations *People living with mental health issues *There are many people who are "eligible" for services under the NDIS, according to the NDIS Act, but are still being assessed as ineligible. People with chronic health conditions that can result in serious functional limitations and people living with mental health issues, are particularly at risk of being erroneously deemed ineligible for assistance, by NDIS assessors. For example, Cystic Fibrosis often results in severe breathlessness, leading to serious functional limitations in terms of communication, mobility and community engagement including employment. Yet evidence

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	<p>shows that less than 13 percent of people with cystic fibrosis who have severe functional limitations, receive the NDIS.</p> <p>*There is a clear need for NDIS planners and assessors to develop a much clearer understanding of the functional limitations that can result from chronic illness and mental health issue, together with the episodic nature that characterises many such disabilities.</p> <p>*To ensure that participants' needs are met, carers' needs are met and NDIS plans are efficient and sustainable, it is essential that carers be involved in NDIS assessment processes</p>
<p>ii. the future of the Information, Linkages and Capacity Building grants program;</p>	<p>The ILC should be addressing the gaps that have been created by the NDIS and how they can be filled; these gaps are those people are not eligible for NDIS.</p> <p>The Information, Linkages and Capacity Building program is of vital importance and more funding is needed to support this program. The Carers Missing Out report highlights the importance of an effective interface between mainstream services and the NDIS. This is the purpose of the Information, Linkages and Capacity Building Program (ILC), however, sector experts suggested that Local Area Coordination (LAC) services are overwhelmed with the demands of supporting people to actually implement NDIS plans. This has limited the capacity of the ILC program to develop a wide range of accessible, community-based support services for people with disabilities excluded from the NDIS.</p>
<p>b. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;</p>	<p>There should be clarity around whose responsibility specific funding is and how it integrates with the NDIS so that people are not left in limbo about whose responsibility it is and leaving them without a service or a less than optimal service.</p> <p>Development of effective referral processes between the NDIS, the Carer Gateway and mainstream support services is essential.</p> <p>Adequacy and appropriateness of Carer Gateway services must be adjusted in response to carer needs.</p>
<p>c. The reasons for variations in plan funding between NDIS participants with similar needs, including:</p> <p>i. the drivers of inequity between NDIS participants living in different parts of Australia,</p>	<p>The recruitment, induction, and ongoing training of those developing plans is essential. It should be based on an understanding of disability, its impact on participants and their carers/family members and how essential support will improve their lives.</p> <p>The checking of plans by participants is essential before final sign off. The input of Carers, where appropriate is also essential to capture the needs of participants in a holistic manner.</p> <p>The Carers Missing Out Report indicates significant inequities between NDIS applicants with similar needs. For people with cystic fibrosis report that there is no correlation between the level of need of the people referred to the NDIS and the likelihood of them receiving an NDIS package. Possible drivers include:</p> <p>*Variation in skill levels of the assessors</p> <p>*Advocacy skills of the person with cystic fibrosis and/or their carers</p>
<p>ii. whether inconsistent decision-making by</p>	<p>Yes see c above.</p>

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the NDIA is leading to inequitable variations in plan funding, and	
iii. measures that could address any inequitable variation in plan funding;	See c above. Improved training for NDIS assessors so that all have a common and consistent understanding of how to assess the functional limitations arising from a disability, rather than focusing on the illness or condition resulting in disability.
d. How the NDIS is funded, including: i. the current and future funding sources for the NDIS,	
ii. the division of funding between the Commonwealth, States and Territories, and	
iii. the need for a pool of reserve funding;	Essential as the NDIS is individualised funding and meant to meet a participant's needs. It is challenging to always be 100% correct with budgeting as circumstances continually change for many people.

On behalf of the NSW Carers Advisory Council and carers across NSW, I ask that you review our feedback taking into consideration needs and the role of carers. We also give permission for our submission to be published.

If you wish to discuss this further, I can be contacted on 0408 020 904 or at NSWCarersAdvisoryCouncilSecretariat@facs.nsw.gov.au.

Yours Sincerely

Prue Warrilow
Chair – NSW Carers Advisory Council