



**Submission to the Joint Standing Committee on the  
NDIS**

June 2020

## About Carers WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends who have disability, mental illness, a chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour. Illness and disability are non-discriminatory and the caring role can be borne by any individual at any given time, regardless of socioeconomic status, age or location. Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems. A report undertaken by Deloitte, Access Economics, 'The economic value of unpaid care in Australia in 2015', determined the replacement value of the care undertaken by carers in Australia to cost \$60.3 billion per annum.

Some important facts about carers include:

- There are 2.65 million unpaid carers in Australia. More than 861,000 carers are primary carers.
- There are more than 230,000 family and friends in a caring role in Western Australia or approximately 1 in 9 in the community.

## Enquiries

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## **1.0 Introduction**

Carers WA wishes to thank the Joint Standing Committee for the opportunity to provide a submission to its inquiry into the National Disability Insurance Scheme (NDIS).

Western Australia is in a unique position as the last state to transition to the NDIS. While this transition was due to be completed in 2020, several delays have extended this deadline. It is expected that WA will have 42,700 at full scheme and 27,277 people were participating at 31 March 2020.

A national scheme to support people with disability is a huge step forward for disability policy in Australia. The scheme's principles of lifetime support, choice and control and individualised planning are welcomed by Western Australian people with disability and their families and carers. The scheme has great potential to improve the lives of people with disability and further facilitate their inclusion in their communities.

Comments provided in this submission highlight the key concerns around the NDIS articulated by carers. The comments are informed by ongoing consultation with carers through individual case studies, carer representation groups and several government funded projects focussing on the transition to the scheme in Western Australia.

## **2.0 Access issues**

The process to gain access to the NDIS requires significant time, knowledge and cost. This work often falls to carers and is in addition to the work they already undertake to support the person they care for. Carers report that there is very little support to prepare the documentation needed for an access request and the process can be confusing and stressful. The LAC partners have a role in supporting people with access requests but in practice are merely providing weblinks rather than providing advice and guidance. Further one on one support is required.

## **3.0 Lack of Support for pre-planning**

Once an access request has been successful the participant and/or their carer enter the NDIS planning cycle. This cycle involves pre-planning; considering participant goals and the necessary supports needed to achieve these goals (informal support, mainstream support and formal support): participation in a guided conversation with an NDIS planner or Local Area Coordinator (LAC) to gather information, develop goals and discuss support; and the subsequent allocation of an individual package of supports (the plan) from the NDIS.

Carers report that little support exists for pre-planning for the initial planning meeting with the NDIS. In order to obtain the support required, the person with disability and/or their carer needs to present a clear picture of ongoing needs for daily care, therapy, community participation, assistive technology and home modification along with draft goals to fit these needs. All needs are required to be justified by assessments and reports from health

professionals. A lack of extensive pre-planning may result in an inadequate plan. The LAC partners have a role in assisting with pre-planning but carers report this is not being delivered.

#### **4.0 Reliance on informal support**

Carers report that if a child or adult lives at home with parent carers the NDIS tends to rely on this "informal support" and does not provide the allocation of funding required for carers to take a break and for people with disability to spend time in the community. The consequence of this reliance on informal support is that carers can become burnt out and are no longer able to provide care.

The NDIS has acknowledged this issue but needs to do more to ensure that carers are supported along with participants. Steps must be taken to sustain informal caring relationships by allowing carers to take a break from their caring role.

#### **5.0 Lack of support coordination**

Once a plan is allocated and approved, people with disability and/or their carers need to engage providers to implement the plan. Carers require support to manage this process, particularly when they are new to the scheme. Carers report receiving a plan in the mail and having no knowledge of how to go about implementing the plan. Support coordination should be mandatory in first plans and also when circumstances change.

#### **6.0 Delays and complications in the review process**

A significant area of stress for carers is the plan review process. The review process can go for many months and this puts an enormous amount of stress on carers while they wait for outcomes. During the time taken to review plans the person with disability can be left without funding support. Carers are also reporting that reviews are taking place over the phone or without contact with the carer at all.

#### **7.0 Thin markets**

The NDIS is predicated on choice and control. However, this choice and control cannot be utilised if service providers are not available to provide supports. There is a lack of both allied health professionals and support coordinators in regional areas of Western Australian. For example, carers have reported that only one support coordinator works in the Northam region of WA. Other carers note that it is difficult to find personal care workers in areas just

outside the regional hub of Bunbury. We acknowledge the work already undertaken on this issue by the NDIS but make the point that this is a significant issue in Western Australia. The issue is exacerbated in remote areas.