

Carers ACT submission to

**Response to the Australian Government Department of Social Services Discussion Paper: Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape.**

**October 2019**

Carers ACT is the ACT body representing the diversity of Canberra who provide unpaid care and support to family member and friends living with a:

- disability
- chronic health condition or terminal illness
- mental illness or disorder and/or
- are frail aged

Nearly 50,000 unpaid carers in the ACT provide care to family members, friends and neighbours. They are an integral part of our aged, health and disability systems. Deloitte Access Economics estimated carers provided 1.9 billion hours of unpaid care nationally in 2018/. The estimated replacement cost of this care with formal care services was \$60.3 billion. \*

**For more information contact:**

Ms Lisa Kelly

Chief Executive Officer  
Carers ACT  
Unit 2, 80 Beaurepaire Crescent  
HOLT ACT 2615  
Telephone: 02 6296 9970  
Website: [www.carersact.org.au](http://www.carersact.org.au)

\*Deloitte Access Economics (2015) the economic value of informal care Australia, 2015 for Carers Australia.

The following principles should be part of the National Disability Insurance Scheme (NDIS; the Scheme) Participant Service Guarantee and include Key Performance Indicators to evaluate how affective they are applied. These Principles may or may not be legislated alongside specific timeframes. *(The following are taken from the Discussion Paper.)*

- Timely - The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.
- Engaged - The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.
- Expert – National Disability Insurance Agency (NDIA) staff have a high level of disability training and understand the impact particular disabilities have on people’s lives. They understand what supports are most effective for a person’s disability.
- Connected - The NDIA works well with governments, mainstream services (Such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.
- Valued - Participants, their families, carers and other support persons feel valued in their interaction with the NDIS and know where to go if they need further assistance.
- Decisions are made on merit -The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.
- Accessible – All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals.

### **Part one**

Carers ACT have evaluated our response from the perspective of the carer and taking into consideration the March 2018 Carers ACT submission to ACT Legislative Assembly Standing Committee on Health, Ageing and Social Service Inquiry on the implementation, performance and governance of the NDIS in the ACT.

Based on the possible principles for the NDIA Service standards the response is based on the information gathered by Carers ACT and based on carers thoughts on what is important for the NDIA to adhere to, and why?

**Timely:** Prompt planning and review is important for carers. If the process is not timely carers and participants must rely on the health system while they wait and risk incurring additional costs. Carers can often care for more than one person with a disability and may have a disability themselves. Carers ACT conducted a survey in 2018 and the results indicated that 76% care for one person with a disability, 15% care for two people, 5% care for three people and 4% care for four people. There are approximately 48,500 unpaid informal carers in the ACT. The change from individual plans to family plans would have a significant impact on our carers and improve timeliness.

**Engaged:** Carers need to be engaged in the process. Carers ACT recommends support coordinators undergo carer awareness training. Carers ACT also recommends part of the

process includes the acknowledgement of carers role as a partner in the care of the participant.

Expert: NDIA staff need a high level of training or staff need to develop specialisation around high priority areas. Carers ACT recommends support coordinators undergo carer awareness training. Carers role to be incorporated into the advice given to participants. Experts need to be able to feed back when participants and carers find there are not enough service ie a shortage of specialist paediatric professionals in the ACT. Planners need to be able to access specialist advice re specific disability if they don't have the knowledge. The Carers ACT survey results indicated that the top five primary conditions are also the top five primary conditions supported by the NDIS. These are: - Autism, Psychosocial disability, Intellectual disability, Physical disability and Developmental delay.

Connected: NDIA working well with government and services helps carers.

Valued: Carers need to be valued in the NDIS process. Carers ACT recommend carer awareness training and mechanism in plan assessment to ensure rights of carers are acknowledged. Carers ACT has recommended that the ACT Government raises with the NDIS the lack of application of the legislation in relation to carers rights to participate in planning and review and their right to determine the level of informal support they are willing or able to provide.

Decisions are made on merit: Both carers and participants need to understand how decisions are made. When an application is declined due to the services being available in the public health system, then the response should include a link to those services to assist the applicant and their carer to locate and use those services.

Accessible: NDIS needs to be accessible to CALD and LGBTQIA+ and others with respect to both participants and carers. With the rollout of NDIS the flow on has been the cessation of funding to many Non-Government Peak (NGO's) bodies that traditionally offered disability services. The wait time between application and approval has impacted on the health of individuals with the removal of key supports services and reliance on the public health system that may not provide those services.

Below is the link to the full report for your consideration and review.

<https://www.carersact.org.au/wp-content/uploads/2018/12/CARERS-ACT-Submission-to-the-ACT-Legislative-Assembly-Inquiry-into-the-NDIS-implementation-in-the-ACT-March-2018-.pdf>

## **Part Two**

This report gathered information, interviewed and meet with individual carers and participants involved with the rollout of the NDIS in the ACT. The committee received 70 submissions, 45 witnesses at seven public hearings held in May and June of 2018.

The report had a total of 30 Recommendations and 40 Findings in the final report. Provided is the link to the full report for your consideration and review.

<https://www.parliament.act.gov.au/in-committees/standing-committees-current-assembly/standing-committee-on-health,-ageing-and-community-services/Inquiry-into-the-implementation,-performance-and-governance-of-the-National-Disability-Insurance-Scheme-in-the-ACT>

**Timely:** The Commission found that children who are born with a hearing loss were not being referred to auditory specialists in a timely manner and therefore were not able to commence therapy before the auditory cortex closed. The impact on health issues requires that a timely and at times expedited to reduce harm on the person. This delay has an impact on long term recovery. Refer to Recommendations 15, 16 and 35.

**Engaged:** Funding of carer awareness training for NDIA planners, Local Area Co-ordinators (LAC) and disability support workers would increase their knowledge of the role that a carer plays in supporting the NDIS applicant. Families with more than one plan could have the option for a family plan. NDIS engaging with the carer and acknowledging the role of the carer and including a carer statement during the initial plan assessment would provide a clear picture of the unpaid care and support that is provided by the carer. Refer to Recommendation 10, 12 and Finding 14, 16, 36 and 39

**Expert:** Recruiting staff with expertise in disciplines can be difficult, especially in a small jurisdiction like ACT. This has an impact on the families that have urgent needs that need to be fast tracked. Looking at new methods of engagement and having face-to-face engagement whilst the NDIS plan is in development will ensure a consistent point of contact and increase the knowledge of the reviewer of the package and increase expertise within NDIS and NDIA. Refer to Finding 8, 16, 37

**Connected:** The implementation of NDIS is a large-scale change and this takes time and support mechanisms to be in place to ensure that all are participating in the scheme. The committee found under Findings 12, 13, 14, 15, 16, 17 and 30. Outstanding items still need to be addressed to ensure that participants and carers have a sense of engagement in the whole process.

**Valued:** Carers want to participate in the decision-making process along with the people they support to ensure that they are safeguarded and advance their human rights, wellbeing and individual interests. Refer to Finding 17, 19 and 20.

**Decisions are made on merit:** NDIS commission does not regulate NDIA complaints and they still are processed by the NDIA. Since the Disability Act has been dismantled this has led to the abolishment of the Last Resort Provider for complaints. NDIA has no published policy on the Provider of Last Resort and this has resulted in people with complex needs not being

supported resulting in excessive demands on carers. Refer to Recommendation 5 and Finding 3, 13, 33

Accessible: The committee found that that NDIS is unlikely to meet the expected 20 per cent participation of culturally and linguistically diverse people with a disability. Ensure Aboriginal and Torres Strait Islander people with disability are well informed. This would also need to apply also to Aboriginal and Torres Strait Islander carers. Refer to Recommendation 8 and Finding 32.

***Another point to note:***

it would assist carers and applicants if all materials produced by the NDIA had the date that it was produced so that they are ensured they are referring to and using the latest material/information.