



**Carers ACT Supplementary information
NDIS Joint Standing Committee Public Hearing 27 March 2015**

About Carers ACT

Carers ACT is the recognised, expert voice with, and for, carers while being the major provider of carer services and supports in the ACT. We are an NDIS registered provider offering a suite of fee-for-service products to people with disability, and we coordinate the ACT and Southern Highlands Commonwealth Respite and Carelink Centres.

Over 43,000 carers in the ACT provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or drug issue or who are frail-aged.

We work closely with government and other support organisations to improve the lives of caring families and individuals throughout the ACT.

Ms Dee McGrath Carers ACT CEO and Carers ACT staff members are attending the Public Hearing, together with ACT carers who have a family member who has become a NDIS participant or was assessed as ineligible. Dee McGrath is a member of the ACT NDIS Expert Advisory Group.

Identified issues

- Respite – or the opportunity for carers and caring families to have a break from their caring

Carers of people with disability have been entitled to access up to 63 days in a calendar year, with additional respite provision under special circumstances. Under the NDIS maximum respite is 28 days, although NDIS Operational Guidelines allow for support to be extended under limited circumstances, or while suitable alternative care support can be arranged. The reduced number of respite days under the NDIS reflects that individual funded packages have the intent to provide additional support to the NDIS participant and allow carers and caring families time to engage in other activities outside their caring role.

From our discussions with caring families it appears that most are unaware of the above provision that allows the NDIA Planner to include additional respite as a reasonable and necessary support.

Carers ACT experience and carer feedback indicates:

- Some carer clients/people with disability who have traditionally received 1-2 days of respite per week have only been approved for maximum 28 days respite each year. Most are receiving 20 days which increases the caring impact on carers and caring families. It also reduces the choice and flexibility of respite for the participant and the carer. Carers are able to purchase additional days from a respite provider at a commercial rate (\$443.71 per night)

that is much dearer (and usually unaffordable for caring families) than the block-funded respite they have accessed before the NDIS Individual Funding Package (IFP) was in place. Under the Commonwealth/State/Territory Mature Aged Carers Agreement carers are able to access additional block-funded centre-based day care that recognises the need to provide necessary support so they can sustain their caring role. Carers ACT is funded to provide a Mature Aged Care Program in the ACT.

A Family Case Study – This ACT family has four children, one with a disability who is now an NDIS participant. Because of the caring load for a child with disability, the mother is unable to participate in the workforce as this child will not attend any social or capacity building activities, including attending school. However, the child enjoyed attending Carers ACT Isaac House two nights a month, which was all the family could afford. This also provided the child with an opportunity to engage with people of similar age and the same gender, as their three siblings were a different gender.

Under the NDIS, the parents were anticipating they could ask for two nights per week respite at Isaac House. The participant's respite component in their NDIS IFP was only assessed at two nights per month. As the family is financially disadvantaged because only one parent is in paid employment, it cannot afford to pay for additional respite (\$443.71 per night) to provide an important social participation activity enjoyed by the NDIS participant, and that would also provide necessary respite for the family. The parents are also concerned they have less opportunity to spend with their three other children and give them 'parent' time without the distractions and challenging behaviour of the child with disability.

- During the NDIA assessment and planning some carers and participants do not include their existing support services as they incorrectly assume these will continue to be delivered outside the NDIS, while others do not mention the need for carer respite during the NDIA planning meeting so IFPs are developed without appropriate support for the carer to sustain their caring role. Therefore, it is important that the NDIS Planner discusses with the person with disability and with their carer (if in attendance) what supports the carer is currently receiving and asks what supports their carer requires so these can be considered in the development of an NDIS participant's IFP.

Carers ACT would like to recommend to the Committee that carers have the opportunity to provide a Carer Statement outlining what support they currently receive, what support is needed for them to sustain their caring role, and other information they think is important when the person with disability they support is assessed for NDIS eligibility. We also recommend that the NDIA promotes the information that carers are able to provide a Carer Statement. The opportunity to provide a Carer Statement should not rely on permission by the person being assessed for an NDIS IFP.

This is particularly important for older parent carers who do not want to discuss their caring capacity or issues they are experiencing in the presence of their adult child. They say that discussing their caring situation in front of their adult child may impact on their relationship, and they don't want to disclose some caring tasks that may embarrass the NDIS participant

e.g toileting needs, their own reduced mobility or capacity to continue their caring role.

- The NDIA Planner is providing respite in a 24 hour block to many participants, rather than it being provided in blocks of hours that provide greater choice and flexibility for carers and participants. For example, so the carer can attend their own regular medical appointments, or participate in a regular social or sports activity.

• Pricing

As an NDIS registered provider Carers ACT understands the challenges of pricing services within the NDIA pricing schedule and the need to maintain a sustainable business model. Our disability services arm – Branch Out Disability Services – provides a suite of products for NDIS participants and non NDIS participants with disability, which were developed in consultation with caring families.

Our experience as a registered NDIS provider as well as carer feedback indicate:

- Pricing for one to one support (ie one support worker to one person with disability) or one to two supports does not adequately cover costs. This means that participants who have lower care needs will be more ‘attractive’ financially to providers as their service price margins can be higher.
- As goal-setting NDIS scheduled prices are more expensive than previously block-funded services there is a trend away from their inclusion in an NDIS IFP and towards the participant or carer accessing these through more cost-effective community funded services. This issue may become more problematic if these services are not sufficiently funded e.g block-funded within the proposed ILC framework or through the NDIS.
- There are still little or no descriptors on most service type items and codes available in an NDIS IFP. This means organisations, such as Carers ACT, need to continually check with the NDIA whether they can charge against them. This is similar for quotable items, such as equipment purchase e.g a wheelchair, which need to go through individual approvals with an increase in red tape.

• Transport

Insufficient community transport has been an ongoing issue for people with disability and their carers and caring families. Many caring families expected that the NDIS would help them solve their transport difficulties and increase opportunities for economic and social participation for participants. Our experience as a carer service provider and carer feedback indicate that insufficient transport funding built into an NDIS participant’s IFP continues to be a key issue for carers. Individual situations include:

- An NDIS participant who previously attended a five-days a week day program received transport support to and from the program over the five days. Under their NDIS IFP transport support was reduced to three days a week as the day service ‘was across the lake’ and they should access a service closer to where they lived.

However, some NDIS participants who live in South Canberra and Tuggeranong indicated there is less program choice in their area compared with North Canberra and Belconnen. If their carer or another family member cannot provide transport for them to participate in the program of their choice their supports under their NDIS IFP are limited.

For some caring families insufficiently funded transport support further increases their carer load, including financial. And, for many frail aged carers who need to provide this transport which may include physically assisting the NDIS participant into and out of vehicles, it can exacerbate their own health issues and reduce the 'respite effect' of supports and activities included in a NDIS participant's IFP.

- Caring families who already subsidise transport costs for their family member with disability to attend day or social programs are concerned that their subsidisation will continue when their family member becomes an NDIS participant. Subsidised travel costs some families between \$500-\$600 dollars every six months. One family, with a young adult child who is still to phase into the NDIS, has refused to pay a second provider additional transport costs as they already pay one provider \$600 for a six month period. See their case study below.

Case study – A young adult with severe and profound disability is still to phase into the NDIS, and whose parents have put in place a program of activities designed to provide a life that is as fulfilling as possible and that supports good psychological and physical health. This young adult is subject to a Falls Prevention Notice and attends all activities in the company of a support worker who assists with all aspects of the activities.

The activities that provide social participation and builds/maintains their physical and psychological capacity are spread across the ACT. On average, 223 kilometres of fully supported travel is required each week. Participation in physical programs are supported by Physiotherapist and Occupational Therapist recommendations.

Parents of this young adult are concerned that the NDIA Planner may not include sufficient transport to support current activities.

- **Lack of independent accommodation support**

While the NDIS does not provide accommodation per se, it has the capacity to liaise with housing providers to provide housing assistance to participants, and also to fund modifications for a person with disability to live independently. Carers ACT is aware that the lack of accommodation support by the NDIS for people to live independently outside their family home is causing significant distress for some participants and caring families.

Currently, a focus for the ACT Government and the ACT NDIA is the transitioning of people living in disability group homes into the NDIS.

Case study – An ACT NDIS adult participant was looking forward to being able to move into independent accommodation, through the support of his NDIS IFP, with a friend who was also phasing into the NDIS. However, the individual’s funded plan included funded support services to remain in the family home rather than support to move into preferred accommodation. This situation is highly problematic as the individual lives with their frail aged mother, who has dementia. She is often often unaware of her adult child or even who her adult child is.

This outcome for the NDIS participant and their friend has not enabled control and choice for either, and is not a sustainable situation for the participant’s frail aged mother (she is 80 years old).

- **Reduced access to domestic-type services**

Many carers have accessed Home and Community Care (HACC) services through Carers ACT, and they are an important aid to help them sustain their caring role. Some carers are advising us that HACC or domestic-type services are being cut from, or not included in, the NDIS IFP of the person they care for. For frail aged carers, who often have poor health or age-related disability, this means they have no or reduced support to maintain their garden or to help clean their house etc. The reduced access to HACC services places an additional load on older parent carers, and has a negative impact on the family’s capacity to continue their caring role.

Similarly, for carers who have a multi-caring role the lack of access to HACC-type services through an NDIS IFP is likely to impact on their capacity to sustain their caring role, and lead to poorer health and wellbeing outcomes for the carer and caring family.

- **Psychosocial disability under the NDIS**

Carers ACT auspices the Commonwealth-funded Mental Health Respite Program, and is funded by the ACT Government to deliver the Mental Health Carer Representation and Participation Program. Because of our engagement with carers of people with psychosocial disability one of our key concerns is mental health respite. We are also concerned about NDIS access for younger people with psychosocial disability.

- **Respite** – Many carers rely on respite and social support provided through the Mental Health Respite Program to help them sustain their caring role, and to maintain their own health and wellbeing. (Because of the intensity of caring for a person with psychosocial disability many carers have mental health issues, including depression and anxiety.)

We are concerned that as mental health respite program funds are being rolled into the NDIS carers will have no or reduced access to respite. We believe that this will be detrimental to both the carer and the person with psychosocial disability who often are supported to live in the community because of the support and interventions (e.g paying rental arrears to prevent eviction) provided by their carer and family.

Carers are also concerned that the person with psychosocial disability they care for will choose not to become NDIS participants even if they are eligible. They are worried about their capacity to continue to care without the support they know could be provided to

eligible participants, including access to respite and the social support respite provides.

- **NDIS access for younger people** – Carers ACT is currently supporting the family of a young person with psychosocial disability who has been unable to access support through the NDIS. See the case study below.

Case study – Carers ACT was contacted by a mental health carer of a teenage family member with a serious mental health condition (anxiety, self-harm, suicidal thoughts) that has significantly impacted their day to day living, particularly schooling, over the past 18 months.

Previously, the family had contacted the NDIA (looking for supports to enable their teenage family member to participate in secondary schooling) and were advised they would need to provide more evidence about the condition being lifelong, or likely to be lifelong. The parents were concerned that if their young teenager learnt that likely had a lifelong condition this would be disheartening, or even devastating. If this young person was eligible for an NDIS IFP they would be phasing into the ACT Trial in this quarter of 2015.

Carers ACT sought support for the family from a senior clinician in the ACT Mental Health Justice Health and Drug and Alcohol Service, and was consequently advised that this situation has been referred to appropriate personnel to see if additional supports could be explored in the absence of NDIA input.

This case study illustrates an apparent lack of fit, or tension, between the intents of the NDIS and a person's lived experience of psychosocial disability, where access to supports means placing the 'permanency' (or likely to have permanent disability) label on the young shoulders of a person who is still developing and maturing – cognitively, psychologically, socially and emotionally.

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