**

**Submission to the Department of Social Services on the Draft Service Concept: ‘Designing the new integrated carer support service’**

Overall, the draft Service Concept, with its strong focus on information provision, peer and counselling support and respite, provides a solid framework for the carer service support model. The following comments are made with a view to strengthening it.

**Monitor the impact of the National Disability Insurance Scheme on carers**

The Australian Government currently funds services for carers through a range of programs of which three are transitioning to the National Disability Insurance Scheme (NDIS): Young Carers Program; Respite Support for Carers of Young People with a Severe or Profound Disability; and Mental Health Respite: Carer Support. As the NDIS is implemented, carers should benefit. Carers, as well as people with significant disability, should feel ‘better off’.

While the guiding principles of the integrated support service system articulate the need for alignment with other policy frameworks such as the NDIS, how this will be achieved needs careful attention in the implementation plan. Families and carers of people with disability will continue to provide substantial support even when the NDIS is implemented. The sustainability of the NDIS depends on families and carers getting the support they need to continue their important role.

NDIS rules and guidelines outline factors that the NDIA must consider when developing participant plans. These include determining whether they need to speak with families and carers when they assess a person with disability and plan their supports. Short cuts in these processes should be avoided.

Although carers cannot be NDIS participants, most should benefit from the funded supports participants receive as they can provide a respite-like effect. The adequacy of this ‘respite’ for carers needs to be monitored. Some carers report that funding for out-of-home overnight support is being reduced in participant plans. It would be concerning if carers are not being included in discussions about these reductions and their likely impact.

Not all people with disability will be participants of the NDIS, but their families and carers may still need information, support or respite. This assistance may be available through the NDIS’s Information, Linkages and Capacity Building (ILC) services but precisely what the ILC will fund has not yet been determined. Carers must have access to the assistance and support that they need.

**Build knowledge about what carer supports work best and for whom**

The draft Service Concept highlights the lack of reliable and robust evidence on the effectiveness of carer supports (including their effectiveness for particular carer sub-groups). The proposed integrated carer support service should be constructed so that it provides information to bridge this knowledge gap.

Carer groups advocate for the use of narrative and qualitative approaches to data collection on carer experiences (to supplement more readily-available quantitative data). NDS supports this approach.

**Multi-component intervention restrictions**

NDS supports early intervention to reduce the extent to which carers experience crisis. The draft Service Concept would be improved by strengthening this aspect.

The concept of a ‘multi-component support package’ (including respite, carer mentoring and financial support) for carers with the greatest need has merit. Unfortunately, the current proposal indicates that only carers found eligible for multi-component support would be able to access any of these three services. NDS does not support this. Each of the elements—respite, carer mentoring and financial support—should be available as a stand-alone service. To not do so would dilute the goal that the new service system is a planned, preventative model (and not one primarily concerned with reactive responses to crises).

**Stronger acknowledgement of the value of respite support service**

The draft Service Concept highlights the low uptake of respite by many carers and the lack of evidence to demonstrate its effectiveness. This assessment is based primarily on research that focused on establishing whether respite is a solution for a range of issues: for example, delaying entry into residential care.

NDS suggests that a more appropriate measure of the impact of respite needs to be developed. For many carers respite is an opportunity to have a break so that they can cope better or maintain their relationship with the person for whom they care. Even when it does not significantly change their circumstances or prolong their ability to care for a family member, it is likely to improve their experience of caring.

In addition, ABS data indicates that respite is very important for some carers, particularly those caring for people with high or complex needs:

* 63% care for 40+ hours per week
* 32% care for someone with a mental or behavioural condition (which includes an intellectual or developmental disability and autism)
* 40% don’t have a fall-back informal carer to assist them
* 15.8% of all primary carers identify an unmet need for respite
* 72% of primary carers who have an unmet need for respite require it on short notice or an irregular basis.[[1]](#footnote-1)

NDS welcomes the acknowledgement of the need for a direct pathway for emergency respite which is separate from the multi-component intervention.

**Improve recognition of family care**

An integrated carer support service should provide options for families who wish to receive services in a whole-of-family context, rather than individually. The draft Service Concept focuses on providing services to individual carers. In many circumstances the caring role cannot be separated from the context of family relationships. This should be acknowledged and available.

**Recognise the needs of carers from minority groups**

NDS is pleased that the draft Service Concept acknowledges the challenges for carers in disadvantaged cohorts, such as young carers; people from Aboriginal or Torres Strait Islander communities; people who have culturally and linguistically diverse backgrounds; people who are from the LGBTIQ community; or people who live in rural and remote settings.

Information and services need to be specifically tailored for these carers. As well as providing information on the types of supports available for both the person they care for and themselves, assistance should be available to help people navigate the respective service systems.

**Design considerations**

NDS provides the following brief comments for the design considerations around the eight service components of the draft Service Concept.

* **Awareness raising, information provision and education** should betargeted and tailored to individual carers’ situations. Access to information and education needs to be available via flexible delivery options.
* I**ntake** should vary depending upon the circumstances of the carer. It should range from a ‘light touch’ for some people who may only be requesting information through to immediate counselling or the provision of emergency respite for those needing it.
* **Peer support** should be readily available through flexible delivery options such as on-line, phone and face-to-face contact points. NDS supports the proposal for carers to register themselves as being available to offer peer support.
* **Needs identification and planning** should be linked to Intake and partly inform prioritisation. This will assist to identify carers most in need at the early stages and reduce the use of more costly services later.
* **Multi-component interventions** NDS supports the delivery of a single package of interventions to carers, but believes that those interventions which have been shown to be most effective should also be available either individually or as a flexible package of carer support services based on need. In addition, the design of interventions needs to recognise that local services and local coordination are important to carers.

**June 2016**

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**National Disability Services** is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes 1100 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

1. Australian Bureau of Statistics, 2012 Survey of Disability, Ageing and Carers. [↑](#footnote-ref-1)