

Carers NSW Supplementary Questions

Implementation of the NDIS and provision of disability services in NSW

Following our appearance at the hearing on the 2 October 2018, Portfolio Committee No. 2 put the following supplementary questions to Carers NSW, with regard to its inquiry into the implementation of the NDIS and the provision of disability services in NSW:

1. Are your members accessing the 90 days of respite that is available from the NSW Government?
2. What respite services should be offered to carers (this may be services that were previously offered, before the NDIS)?
3. Are you aware of the contracting of the NDIA that commenced in early July that reportedly requires nine providers (Marymead, Northcote, the Australian Foundation for Disability, Life Without Barriers, Uniting and Live Better) to act as a provider of last resort?

Our responses to these supplementary questions are addressed in chronological order below.

1. Are your members accessing the 90 days of respite that is available from the NSW Government?

Carers NSW is aware of a 90 day threshold which triggers the need for a case plan to be made for children accessing voluntary out of home care (VOOHC). To our knowledge, this 90 day period may or may not be respite, and therefore cannot be considered a respite service per se. Further, not all children using these 90 days of VOOHC have a disability. Finally, 90 days is not an entitlement but rather an administrative threshold that triggers a particular service response.

If this is not the “90 days of respite that is available from the NSW Government” that the question is referring to, Carers NSW is unsure what is meant by the question.

With regard to the service use of our membership, not all members of Carers NSW are clients of our programs and carers do not need to be a member to receive services from Carers NSW. As a result, the two databases are separate, meaning that determining whether our members are accessing any particular service is difficult. Further, VOOHC services would only be available to a small proportion of our membership - carers of children, so referral would be unlikely to be very high.

However, as stated, Carers NSW does not consider the 90 days of VOOHC that triggers a case plan to be put in place as an entitlement to access a respite service.

2. What respite services should be offered to carers (this may be services that were previously offered, before the NDIS)?

Our response to this question is broken into three sections: context, findings and recommendations.

Context

Prior to the transition to the NDIS, Ageing, Disability and Home Care (ADHC) provided and funded a range of activities for people with disability with the aim of providing a break for carers, including own home respite, host family respite, peer support, flexible respite, after school and vacation care, respite camps, centre-based respite (planned short term breaks in a respite centre) and emergency respite. Other ADHC funded programs also provided some respite, including the NSW Community Care Supports Program (CCSP) and early intervention supports. As a result of the closure of ADHC on 30 June 2018, the NSW Government no longer funds or delivers respite, other than (in a very limited

capacity) through voluntary out of home care (VOOHC), referred to in our response to Question 1, through the child protection system.

In addition to ADHC, a number of Commonwealth funded programs previously offered respite. The Department of Social Services (DSS) National Respite for Carers Program (NCRP) funded, among other services, planned and emergency respite through 54 Commonwealth Respite and Carelink Centres (CRCC) across Australia. The function of CRCCs is due to be taken over by the new Integrated Carer Support Service, rolling out across 16 service delivery regions from September 2019.ⁱ

The ICSS is intended to replace the CRCCs in linking carers to planned and emergency respite services in their local community,ⁱⁱ which may address some respite need previously covered by ADHC and DSS programs. However, the actual provision of respite under the ICSS is limited to emergency respite, brokered to existing providers, and to a very limited amount of other respite activities that may be accessed by some carers under small, funded packages.ⁱⁱⁱ

The other DSS funded respite programs in scope for transition to the NDIS are:

- Mental Health Respite: Carer Support (MHR:CS), which provided carers of people living with a mental illness with a break from the caring role through in-home or out-of-home respite or social and recreational activities (and which Carers NSW has delivered in two areas of NSW)
- Respite Support for Carers of Young People with Severe or Profound Disability, which provided immediate and short-term respite for carers of people under the age of 30 years (and those experiencing significant stress in caring for a person with a disability under 65 years of age) whose needs are not being met through existing state or territory government initiatives (though delivered by CRCCs, services have transitioned to the NDIS)
- Young Carers Respite and Information Services, which assists students with a significant caring role who need support to complete their secondary or vocational education. It has two components: respite and education support services for students up to 18 years of age (delivered by CRCCs nationwide) and information, referral and advice services (delivered by Carers Australia and the National Network of Carers Association).

While some of the support categories funded in NDIS plans overlap with the functions of respite as it existed under ADHC and DSS, there is no longer an emphasis on carers' needs in relation to these support types, and their scope has been considerably downgraded. Supports provided in an NDIS plan can provide a respite effect, and even mirror support types that were previously called respite, for example, short-term accommodation and community access, however, NDIS supports focus on the needs of the participant and are not required to assess or address the carer's needs. There is therefore no guarantee that a carer of an NDIS participant will receive the respite effect that they need; and yet, the ICSS model assumes that planned respite is no longer needed.

The ICSS model also presupposes that RDPs will be able to work with, leverage and refer to a network of existing local services, including both planned and emergency respite, which are not guaranteed to continue in their current forms. Carers NSW is highly concerned that the coverage of respite under the ICSS remains limited and reliant on referral to local services, which in NSW may no longer exist due to sector reforms, especially in regional, rural and remote areas.

In the current and emerging service landscape in NSW, there appears to be very little availability of planned breaks from the caring role which are focused on the needs and preferences of the carer, designed to enhance their health and wellbeing. Many carers continue to report their own need for a break not being met. The loss of carer-focused breaks extends beyond conventional respite service arrangements; carers also report that after school and school holiday care is not being included in

NDIS plans for school aged children, citing the Department of Education's responsibility to address this need. However, many carers note that their child's needs are too high for them to be safely accommodated in mainstream programs, causing them to reduce their working hours or leave work completely.

Planned breaks also include funded recreational and peer support opportunities that take the carer away from the caring role and enable them to invest in their own health and wellbeing. Before the NDIS, such activities were funded under the *together* program, Mental Health Respite: Carer Support and the Ageing Parent Carer Support Coordination Program. Many carers have limited disposable income, and considerable additional costs related to the condition of the person they care for, making recreational and self-care activities a low spending priority.

While a number of government programs will continue to fund peer support, the sustainability funding previously provided by the *together* program in NSW will not be replicated. These small annual grants have enabled many carer support groups to cover venue hire, catering costs and the costs of guest speakers and recreational activities, which may have otherwise been unaffordable. The only grants available to carer support groups for such items moving forward are the annual Carers Week Grants, which focus on events. Volunteer-led groups, especially those working with disadvantaged and isolated carer cohorts, are particularly likely to be disadvantaged, as will groups who are unlikely, or unable, to access the largely online peer support resources being developed with ICSS and FACS funding.

Carer retreats are another type of carer focused planned break that seem to have disappeared completely from the service system since the NDIS rollout. Such retreats were funded under various block-funded programs in NSW, and enabled carers to spend extended time outside of their caring role, investing in health and wellbeing activities, peer support and often education and capacity building programs.

Carers NSW also wishes to point out that it is not only carers of NDIS participants who may lose, or see a reduction in, their access to respite. Not all people with disability in NSW will be eligible for, or otherwise able to access the NDIS, eliminating even the possibility of accessing supports that will have an indirect 'respite effect.' While most former ADHC clients were in scope for direct transition to the NDIS, many of those accessing respite and community and in home support were required to apply to confirm their eligibility. These are generally isolated, vulnerable people with mild to moderate disability and/or functional impairments resulting from a health and mental health conditions and complex disadvantage. Many of these people and their carers will be ineligible for, or otherwise unable to access, the NDIS, and will therefore lose the support they had been accessing previously.

Findings

In the Carers NSW 2018 Carer Survey, conducted between May and July 2018, the 1,830 carers who responded were asked about their usage of four types of carer support: respite, carer support groups, counselling and online forums. While respite was the most commonly used of these support types, used by 43% of respondents, more than one third of those using respite (37%) reported that they would like to use it more.^{iv} Recent focus groups with carers from six culturally and linguistically diverse (CALD) communities in NSW confirmed that a break from the caring role, with a focus on funded recreational activities and peer support, is many carers' highest priority.^v

Other surveys conducted by the National Network of Carers Associations (the Network) with carers of people of all ages and with a range of conditions (i.e. not only people with disability under the age of 65) have produced findings that support the need for a greater understanding of demand for respite. A

survey conducted by Carers NSW in 2016 (on behalf of the Network) with 1,803 carers¹ across Australia found that:

- Carers saw respite primarily as a way of getting a break and maintaining their health and wellbeing
- Many carers wanted to use respite services but do not because they cannot find services that suit their needs
- A lack of information about respite options, complicated pathways to access respite and the cost of respite prevented many carers from accessing it^{vi}

More than one in three respondents (37.4%) had never used respite. However, of those who had, 40.2% had used it regularly. Satisfaction with respite increased considerably when respondents had used respite more frequently, suggesting that the key issue with respite is the amount available to carers. The relatively large proportion of respondents who had not used respite before, or very often, did not simply reflect a lack of need. Respondents indicated that the main reasons for not accessing respite had to do with factors such as difficulty finding out about and successfully accessing respite options, and a shortage of options appropriate to the individual needs of the carer and care recipient.^{vii}

The following quotes from respondents highlight some of the key aspects of respite that carers prioritised:^{viii}

“Respite needs to be made more accessible to carers rather than having to ring around various departments and being put on a waiting list that you never hear back from.”

“The person I care for dose [sic] not want to go & there are no respite centres that cater for young adult high functioning mental health.”

“Staff not allow to give injection to clients. My son is a diabetic, insulin dependent and needs at least 3 injections per day.”

“Both Primary Carers are shift workers, starting between 05:00 and 07:00, unable to find any organisation to provide respite/care early in the morning so both can go to work and also put client on the bus to School at 08:15.”

“Am in need of it now, but if any places are available they aren't available when we need it. So surgeries are deferred, or any idea of a short holiday (even a weekend) is quashed.”

“The times that I have tried to access respite options they cannot provide the support as it is either on the weekend or in the evenings.”

“I don't use it because I don't think it is up to standard nor do I think the staff are properly qualified or supervised.”

In 2017, Carers Australia conducted a survey of CRCCs and other services that refer carers to respite on behalf of the Network, in the context of residential aged care, but with findings relevant to, and consistent with, issues raised in the disability sector. A total of 112 responses were received from across Australia, with the majority of services operating in regional, rural and/or remote areas (74 per cent), while less than half (44 per cent) operated in metropolitan areas. The survey results made it very clear that demand for residential respite care was not being met. Both planned and emergency respite were reported to be in high demand, especially in home respite care. All types were reported as difficult to access and not always available to refer carers to. Key barriers to accessing respite

¹ Respondents were not limited to carers of people with disability.

identified by respondents were: low availability, high care needs and affordability. Proposed solutions included increased supply of all types of respite, especially those catering to high support needs, and options that are better tailored to the needs of consumers and carers. ^{ix}

A further paper was published by Carers Australia in October 2018, with regard to respite in the context of the NDIS. This paper, which focused on the policy and rationale of the NDIA in relation to the provision of respite, recommended that the NDIA's expectations with regard to informal care and reasonable and necessary support better reflect carers' needs, and that opportunities to access respite-like supports be highlighted to carers of NDIS participants. ^x

In order to progress solutions to the current lack of respite supply, Carers NSW established a working group in 2017 called the Carer Respite Alliance (CRA). ^{xi} The stated purpose of the CRA is to draw on existing knowledge about carer respite held by member organisations to identify key issues and solutions, conduct evidence based advocacy to raise awareness about carer respite issues and effect change, and work together to increase the knowledge base on carer respite. The CRA is currently working on developing a comprehensive paper that addresses what 'respite' means across a range of sectors, whether it is effective as a service type and what carers prioritise as most important in accessing respite. The report will draw on existing publications produced by members and ongoing research and evaluation.

Recommendations

With respect to the context and findings presented, Carers NSW makes the following recommendations with regard to respite in NSW:

- Ongoing funding is required for planned respite in a variety of settings including at home, centre based and overnight respite for carers of NDIS participants who have not been successful in receiving equivalent support under the NDIS, and for carers of people with disability who are not eligible for an NDIS plan
- Organisations with respite programs and infrastructure for whom running these services is no longer viable due to funding changes should be supported to maintain these functions, making them available to the above groups
- Families of children with disability requiring VOOHC, which is not funded by the NDIS, should be funded separately to children under the child protection system to access residential respite
- Organisations that run volunteer led community based respite, such as host family respite, should continue to be supported to do so in a financially viable manner, taking into account the costs associated with training and managing volunteers
- Fully funded and subsidised recreational, educational and peer support activities targeting carers should continue to be a priority for governments, given that these opportunities are often low cost alternatives to other forms of respite and provide carers with a meaningful and refreshing break
- All respite should be flexible and tailored to the needs of individual people with disability and their carers, providing choice and control as to where, when and how support is delivered.
- Parents of children with disability should be afforded the same access to long day care, holiday programs and after school care services as all other parents in NSW. To achieve this the NSW government will need to provide child care options for parents of children who cannot be supported by local child care services as well as supporting early childhood centres to have the capacity to support children with disability.

3. Are you aware of the contracting of the NDIA that commenced in early July that reportedly requires nine providers (Marymead, Northcote, the Australian Foundation for Disability, Life Without Barriers, Uniting and Live Better) to act as a provider of last resort?

Carers NSW is aware that these service providers have been contracted to provide an emergency response, however we do not believe that these providers fulfil the role of a provider of last resort.

To our knowledge, these providers represent an escalation pathway available only to health and law enforcement staff to directly refer people with disability to out of hours or in other urgent circumstances where ordinary modes of support are unavailable. Contrary to a suggestion made at the hearing, it is our understanding that this service is *not* available to people with disability, their families and carers directly, nor to their coordinators of support, and provides a time-limited, emergency response to cover basic needs only. Emergency and escalation pathways do not equate to the provision of last resort.

Carers NSW explicitly addressed the issue of provider of last resort in our pre-budget submissions to the NSW Government for the 2015-16, 2016-17 and 2017-18 State budgets.^{xii} We define the provider of last resort as the organisation or organisations who are not entitled to turn any prospective service user away for any reason. The provider of last resort acts as a safety net for the most vulnerable people with disability in our society, and safeguards those who, due to complex support needs and/or behaviours of concern, may be declined service by other providers. Until its closure on 30 June 2018, ADHC played this role.

In a market based service system, where markets in certain areas are thin and small to medium providers are struggling to stay in business, cost pressures will ultimately mean that some people with disability will be seen as too costly to service and will be turned away. While there is no formal provider of last resort for people with disability, those rejected by the system are at high risk of crisis, and are likely to wind up having unnecessary, extended stays in hospital, staying long term in inappropriate aged care facilities, sleeping rough on the streets, or living in high-stress, unsustainable arrangements with family members or friends.

The nine providers contracted by the NDIA to respond to emergency referrals are not, to our knowledge, expected to offer ongoing services to people with disability whose needs cannot be met by service providers in their area. Therefore, they do not function as providers of last resort.

ⁱ DSS (2018) *Carer Gateway service areas*, available online at: https://www.dss.gov.au/sites/default/files/documents/09_2018/carers_gateway_service_areas_fact_sheet.pdf, last accessed 22 October 2018.

ⁱⁱ DSS (2018) *Carer programs – what is changing?* Available online at: https://www.dss.gov.au/sites/default/files/documents/09_2018/carers-programs-what-is-changing.pdf, last accessed 22 October 2018.

ⁱⁱⁱ DSS (2018) *Appendix A: ICSS Service Blueprint*, available online at: https://www.dss.gov.au/sites/default/files/documents/09_2018/icss-service-blueprint.pdf, last accessed 22 October 2018.

^{iv} Carers NSW (2018) *Carers NSW 2018 Carer Survey: Summary report*, available online at: <http://www.carersnsw.org.au/Assets/Files/FINAL%202018%20Carer%20Survey%20Report.pdf>, last accessed 22 October 2018.

^v Carers NSW (2018) *Focus groups with culturally and linguistically diverse carers in NSW: Summary of findings*, available online at: <http://www.carersnsw.org.au/Assets/Files/Carers%20NSW%20CALD%20Focus%20Groups%20Report.pdf>, last accessed 22 October 2018.

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- vi Carers NSW (2017) *Give us a break: Evidence that Australian carers still need respite*, available online at:
http://www.carersnsw.org.au/Assets/Files/Give%20us%20a%20break_Evidence%20that%20Australia%20carers%20still%20need%20respite.pdf, last accessed 22 October 2018.
- vii Carers NSW (2016) *National survey of carers' respite needs: Final report*, available online at:
<http://www.carersnsw.org.au/Assets/Files/Respite%20Survey%20Report.pdf>, last accessed 22 October 2018.
- viii Carers NSW (2016) *National survey of carers' respite needs: Final report*, available online at:
<http://www.carersnsw.org.au/Assets/Files/Respite%20Survey%20Report.pdf>, last accessed 22 October 2018.
- ix Carers Australia (2018) *Improving access to aged residential respite care*, available online at:
<http://www.carersaustralia.com.au/storage/residential-respite-care-report.pdf>, last accessed 22 October 2018.
- x Carers Australia (2018) *Position paper: NDIS reasonable and necessary supports – the case for respite*, available online at: <http://www.carersaustralia.com.au/storage/carers-australia-positon-paper-ndis-reasonable-and-necessary-supports-the-case-for-respite-1.pdf>, last accessed 22 October 2018.
- xi Carers NSW (2018) 'Carer Respite Alliance', *Speak up for carers*, available online at:
<http://www.carersnsw.org.au/get-involved/campaigns#Section3>, last accessed 22 October 2018.
- xii Carers NSW (2014) *Supporting carers: achieving the vision, Carers NSW 2015-16 pre-budget submission*, available online at:
<http://www.carersnsw.org.au/Assets/Files/Supporting%20carers,%20achieving%20the%20vision-%20Carers%20NSW%202015-16%20pre-budget%20submission%20Dec%2014%20.pdf>, last accessed 22 October 2018; Carers NSW (2015) *Making it happen for carers: Carers NSW 2016-17 pre-budget submission*, available online at:
<http://www.carersnsw.org.au/Assets/Files/Making%20it%20Happen%20for%20Carers-%20Carers%20NSW%202016-17%20pre-budget%20submission.pdf>, last accessed 22 October 2018; Carers NSW (2016) *Putting carers first: Carers NSW pre-budget submission*, available online at: <http://www.carersnsw.org.au/Assets/Files/PBS%202017-2018%20FINAL.pdf>, last accessed 22 October 2018.