



Getting it right for carers

**Carers NSW Pre-Budget Submission
2019-2020**

ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

www.carersnsw.org.au

<https://twitter.com/CarersNSW>

<https://www.facebook.com/carersnewsouthwales/>

ABOUT CARERS

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

Across NSW, there are approximately 904,400 carers,¹ and to replace the care they provide the NSW Government would have to spend more than \$17 billion each year.² Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

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¹ Australian Bureau of Statistics (2017) *Disability, Ageing and Carers, Australia: Summary of findings, 2015*, New South Wales Tables, Canberra.

² Carers NSW estimate based on Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015*, Carers Australia.

INTRODUCTION

In June 2018 the NSW Government ceased delivering specialist disability and community care supports with the closure of Ageing, Disability and Home Care (ADHC). This also marked the completion of the formal transition of State funded disability services to the National Disability Insurance Scheme (NDIS) in NSW.

Between June and October 2018, the NSW Legislative Council Portfolio Committee No. 2 examined the effectiveness of this transition based on evidence from 350 public submissions and two public hearings, which identified a range of inefficiencies, inequities and service gaps affecting people with disability, their families and carers.

October 2018 also marked the commencement of development and testing for a range of new, online carer supports linked to the Carer Gateway, following the announcement in September 2018 of the regional delivery framework for Commonwealth funded carer supports under the new Integrated Carer Support Service (ICSS). By September 2019, all remaining Commonwealth carer support funding will have been reallocated to 16 new regional delivery partners (RDPs), including four in NSW.

The extent and pace of change in the carer support sector in NSW since the last State Budget has been unprecedented. Between now and the end of the 2019-20 financial year, an entirely new Commonwealth carer support system is expected to be in place. The State Budget for 2019-20 must therefore ensure that adequate funding is allocated towards the smooth transition of carers in NSW to this new system. Now is the time to 'get it right' for carers in NSW.

This Pre-Budget Submission highlights three broad areas requiring ongoing and additional investment from the NSW Government, detailing key issues, evidence and recommendations. These recommendations are based on extensive consultation with carers, staff and other stakeholders working with carers across NSW.

Carers NSW urges the NSW Government to:



1. Keep championing carers



2. Stay in the business of carer support



3. Help carers navigate complex service systems

1. KEEP CHAMPIONING CARERS

The NSW Government has a strong history of supporting carers, with the NSW *Carers (Recognition) Act 2010* (the Act) and the NSW Carers Strategy 2014-2019 (the Strategy) setting a leading example nationally for whole-of-government carer recognition and support at a State level.

Carers NSW commends the NSW Department of Family and Community Services (FACS) for demonstrating its continued commitment to supporting carers at a time of massive sector change by delivering on the Strategy and providing \$5.6 million over three years from July 2018 to fund a range of innovative projects under the Carer Investment Program (CIP).

Carers NSW is pleased that the State Government recognises the ongoing need for investment in support for carers at a State level. However, with the closure of ADHC, we are concerned that gaps in direct and indirect carer support will continue to widen as the ICSS rolls out in NSW and as carers continue to adjust to the NDIS. We are also concerned that parts of Government may incorrectly anticipate that their role in supporting carers will no longer be needed following these rollouts.

Now, more than ever, carers in NSW need continued and targeted support from their State Government. This will only be achieved if carers remain a priority in whole-of-government policy, strategy and expenditure. Therefore, Carers NSW makes the following recommendations to the NSW Government for the 2019-20 financial year:

Recommendations

- Maintain a voice for carers within Cabinet (pp. 4-5)
- Fund the development and implementation of the new NSW Carers Strategy (p. 5)
- Make successful carer programs sustainable (p. 5)
- Continue to invest in the Carers + Employers network (pp. 5-6)
- Enhance carer recognition in the public sector (p. 6)
- Increase carer awareness in the community (p. 6)

Maintain a voice for carers within Cabinet

There has not been a ministerial portfolio with 'carers' in the title for some time. However, successive NSW Ministers for Disability Services have worked to represent the interests of people with disability, their families and carers within Cabinet, within Parliament and in their interactions with the Commonwealth.

Carers NSW argues that maintaining a ministerial portfolio that explicitly addresses the needs of carers is not only consistent with the Act, but will also be critical in ensuring carers remain a whole-of-government priority throughout the ongoing transitions to the NDIS and ICSS.

The recently reviewed and amended Act still mandates the existence of a Carers Advisory Council (the Council) that advances the interests of carers and advises the Minister for Disability Services on matters of policy and legislation. A ministerial portfolio of direct relevance to the work of the Council will therefore be required on an ongoing basis, as well as a section of FACS responsible for liaising with the Council and advising the Minister.

Explicitly reintroducing carers to a ministerial portfolio will help ensure that the implementation of the Act and Strategy are prioritised at Cabinet level and safeguard the interests of carers as the NDIS and ICSS continue to roll out in NSW.

Fund the development and implementation of the new NSW Carers Strategy

The co-design and delivery of the current Strategy has led to invaluable opportunities for carers, stakeholders and communities to increase their understanding of the challenges facing carers in NSW and the action taken to address them. The Strategy is due to end in 2019 and Carers NSW understands that FACS intends to develop a new Strategy from 2019.

This will be a challenging yet timely period to establish a new Strategy, given the many recent, ongoing and imminent changes to the carer support sector within NSW and nationally. Carers NSW looks forward to a thorough, evidence-based and consultative co-design process and urges the NSW Government to allocate sufficient funds to the Strategy's development, refinement, implementation and evaluation.

Make successful carer programs sustainable

The 14 projects funded by the CIP reflect a welcome emphasis on carer employment, peer support, health and wellbeing and on young carers and Aboriginal and Torres Strait Islander carers. Investment in targeted projects addressing these areas of need is critical and Carers NSW commends FACS for providing ongoing funding to such projects.

However, as these projects are time limited, Carers NSW wishes to stress the importance of planning for ongoing expenditure in these areas, as carer support needs will not be comprehensively picked up by the NDIS and ICSS, or by other Commonwealth funded programs and initiatives investing in carers, such as the Try, Test and Learn fund and Commonwealth Home Support Program.

Further, it is not only FACS that should continue to fund carer projects and programs. Subsequent sections of this submission will highlight the importance of ongoing funding to the NSW Health funded programs in local health districts (LHDs) and the Family and Carer Mental Health Program, as the supports they currently provide may not be adequately replicated within Commonwealth schemes.

Initiatives funded by other departments should also be leveraged to expand and improve support to, in particular, young carers experiencing social and financial disadvantage and carers of all ages seeking education and employment. Programs such as Opportunity Pathways, Smart and Skilled and Youth Frontiers offer supports for which many carers may be eligible, but are yet to directly target and support carers as a key cohort. Carers NSW believes that opening up these programs to carers as a target group will lead to better connected, more holistic, and cost-effective carer support across NSW.

Continue to invest in the Carers + Employers network

Nearly one third of all working age carers are not in the labour force, compared to one in four non-carers (20 percent), with many exiting the workforce due the challenges of balancing work and care. Of those carers that are employed, many limit their career progression to maintain flexibility.³ While in some circumstances the extent of caring responsibilities makes it unfeasible for carers to continue working, many other carers can remain in the workforce with improved employer support.

³ ABS (2017)

The Carers + Employers network is a newly established membership based network of employers seeking to enhance the workforce participation of carers. The network, currently funded by FACS and DSS, aims to promote carers' rights within the workplace, share best-practice and develop strategies which attract and retain working carers. At the time of writing, 18 major employers have either committed to or expressed interest in participating in the initiative

Despite the strong interest and the early stages of the project, the network only has funding secured until March 2019. Membership fees will be introduced in order to cover the cost of resources and training and support the ongoing sustainability of the network. However, additional funding will be required in the short to medium term to ensure a smooth transition to a fee for service model. Ongoing investment from FACS for the 2019-20 financial year will enable Carers NSW to continue employing a staff member to expand and coordinate the network, conduct outreach, take enquiries and conduct workplace assessments until the network is self-sufficient.

Enhance carer recognition in the public sector

Since its enactment in 2010, the Act has received increasing attention within the public sector, largely as a result of concerted efforts by FACS and other stakeholders including Carers NSW to promote the NSW Carers Charter (the Charter) and to hold agencies and departments accountable to their legislated obligations.

However, in 2018, Carers NSW still finds that many departments and agencies are unaware of the Act and the principles and requirements it sets forth. As a result, much of the public sector is not reflecting the level of carer recognition, inclusion and support that the Act was established to deliver.

The recent review and amendment of the Act provided a timely opportunity to revise and clarify the Charter and to produce new promotional resources regarding the Act for a range of audiences. Carers NSW is supportive of the initiative taken by FACS thus far in promoting the amended Act, but believes more investment in resources and promotion is required in order to raise awareness of public sector obligations and uphold the principles of the Charter.

Increase carer awareness in the community

In the experience of Carers NSW, awareness of the Act and Charter also remain relatively low among carers and within the broader community. Concurrently, carers continue to report a relatively low level of recognition within their own communities. The Carers NSW 2018 Carer Survey⁴, conducted in May to July 2018 and receiving 1,830 valid responses, found that only one in four carers who responded felt recognised by their community.

New resources developed and distributed by FACS regarding the Act and to promote carer recognition and identification in the broader community represent important steps toward improving carer recognition. However, more community focused resources are required. There is a particular need to raise awareness of carers in NSW, support hidden carers to identify and access support, and empower carers, employers, service systems and community groups to understand the value of carers and their entitlement to respect and support.

⁴ Carers NSW (2018a). *Carers NSW 2018 Carer Survey: Summary report*, Retrieved from: <http://www.carersnsw.org.au/research/survey>.

2. STAY IN THE BUSINESS OF CARER SUPPORT

As a result of sector reforms, the majority of State and Commonwealth carer support funding has either already transitioned, or will soon transition, to the NDIS or ICSS.⁵ By the end of the 2019-20 financial year these transitions are intended to be complete. Many of the outcomes achieved under prior carer support programs will be replicated within these two systems, and new types of support will be offered.⁶

However, Carers NSW is concerned that some carer support outcomes are receiving less attention under the NDIS, ICSS and aged care system than they did previously, resulting in reduced overall support for many carers. People with disability and older people who are ineligible for packaged support or who are otherwise unable to access it are also experiencing reductions in service ultimately impacting carer wellbeing.⁷

Furthermore, the NDIS and ICSS assume the ongoing existence of State and Territory services to which carers and people with disability can be referred. However, in NSW currently, residual carer and disability supports are minimal. Additional, ongoing funding from the NSW Government will be required to maintain the necessary infrastructure to support the implementation of the NDIS and ICSS and to act as a safety net for carers whose needs are not being met under these systems.

The 2019-20 financial year will be a key period for the NSW Government to closely monitor these emerging gaps and respond with strategic, long term solutions. Accordingly, Carers NSW makes the following recommendations:

Recommendations
<ul style="list-style-type: none">• Maintain support for carers of children (pp. 7-8)• Maintain a safety net for people ineligible for the NDIS (pp. 8-9)• Maintain critical respite infrastructure (p. 9)• Continue to invest in carer wellbeing (pp. 9-10)

Maintain support for carers of children

With the closure of ADHC and the transition of clients to NDIS packages, several programs directly benefiting the parents of children with disability are at risk of being lost. These include the implementation of 'train the trainer' sessions for the Triple P Stepping Stones program, inclusive vacation and after school care options, and voluntary out of home care (VOOHC).

Triple P Stepping Stones is a longstanding, evidence-based capacity building program for carers, previously funded by ADHC in a 'train the trainer' capacity to support organisations in equipping parents of children with disability to better manage their child's behaviour. While education and behaviour support delivered to parents of children are within scope for NDIS funding, and carers of NDIS participants could technically pool their funding to access group-based supports such as this

⁵ Carers NSW (2018b). *Carers NSW submission: Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales*. Retrieved from www.parliament.nsw.gov.au; Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L, Goode, A., Walton, H., Smith, L., Wei, Z., Flavel, J. (2018). *Evaluation of the NDIS: Final Report*. Retrieved from www.dss.gov.au

⁶ Carers NSW (2018b).

⁷ Carers NSW (2018c) *Project Report: Carers of people ineligible for individually funded support packages in NSW* (unpublished).

package funding makes scheduling group training difficult. Similarly, despite the existence of ILC grants which could potentially support the block funded rollout of this program, ILC resources have been slower to rollout in NSW than anticipated. Furthermore, not all parents of children with developmental delay will have access to NDIS funding, and the capacity of ILC grants to meet carers' particular needs are limited.

Carers of children accessing the NDIS are continually reporting to Carers NSW that care outside of school hours is not being funded, as inclusive vacation and after school care are considered to be the responsibility of the NSW Government. However, in some cases children's support needs are too high to be safely accommodated by mainstream services, leaving parents with no other option than to reduce or relinquish their paid employment. Either these programs urgently need to become more inclusive, or additional support needs to be funded by the NSW Government to enable these children to access mainstream services.

Fatimah's son Mohamed is non-verbal and exhibits behaviours of concern. When his plan was reviewed, the funding allocated to Mohamed was drastically reduced, leaving no funding at all for vacation care. This loss of funding greatly distressed Fatimah, who will not be able to work.

VOOHC is another support type that is deemed to be outside the scope of the NDIS. It is our understanding that families of children are not eligible for funded short term accommodation in their NDIS plan, as ongoing care in the home is considered to be a reasonable expectation of a parent. Despite this, VOOHC has been a key support available to families in NSW whose children with disability require temporary care in a residential environment to support their own safety and wellbeing, and that of their parents and siblings.

While out of home care continues to be available within the child protection system, Carers NSW believes that a separate pathway for families of children with disability should continue to exist, acting as a safety net for families in crisis who may be otherwise unable to access a needed break to support the sustainability of family care arrangements.

Maintain a safety net for people ineligible for the NDIS

Carers NSW commends the NSW Government on its commitment in the 2018-19 State Budget to maintain some residual disability supports in order to assist people with disability, their families and carers with their transition to the NDIS. The extension of the Pathways Project to clients of the Community Care Supports Program (CCSP) who had previously been unable to access the NDIS, the continuation of funding to Ability Links NSW, and the establishment of the Integrated Service Response (ISR) and the Safe and Supported at Home (SASH) program were positive responses to ongoing challenges facing people with disability, their families and carers navigating the NDIS.

However, evidence suggests that there will remain a cohort of people with disability, their families and carers in NSW who are ineligible for the NDIS and for whom time-limited and capacity-building focused supports such as these will be inadequate. These former ADHC clients and newly diagnosed or discharged people who would have been eligible for support from ADHC, require ongoing, practical support as the result of functional impairment that is either deemed too low

"I have failing health and use a wheelchair and am housebound with an advanced degenerative neuro-immunological disease...my claim for NDIS for self was refused citing illness is not a permanent lifelong disability."

- 2018 Carer Survey respondent

for the NDIS, or results from one or more conditions considered to be the responsibility of the health system.

Given that the Safe and Supported at Home (SASH) program only provides support for six weeks at a time, with limited opportunities for renewal, the only remaining options for ongoing, in-home support for people ineligible for the NDIS are referral to the aged care system (where support is rationed, attracts a co-payment and is subject to extensive waiting lists); purchasing private services (which may not be affordable) or leveraging mainstream services, community and informal supports (which are not always available, sustainable or adequate). In order to prevent increased costs to carers, as well as the risk of unsustainable caring arrangements affecting carers' wellbeing and social and economic participation, support must be available for a longer duration at no cost.

Lorraine has been caring for Errol for the past 20 years. He has a spinal cord injury and health related complications that have left him with chronic pain and severe depression. They applied for the NDIS but Errol was knocked back, even after appeal. Since the CCSP ceased, Lorraine and her husband Errol have no longer been receiving in-home support. Lorraine is not coping and has experienced mental health problems herself.

Maintain critical respite infrastructure

In addition to funding activity and peer support expenses, ongoing investment in respite infrastructure – facilities and operational costs – is critical. The ICSS model presupposes that RDPs will be able broker and refer to emergency respite. However, demand for residential respite currently outstrips supply in the aged care sector,⁸ and service providers in the disability sector are finding it more and more difficult to continue operating and maintaining respite facilities catering to under 65s, due to the narrow margins associated with prices for NDIS supports.⁹

“As NDIS has repeatedly underfunded my daughter’s plan for respite, we are currently halfway through her current plan & there is no money left...Now that her respite house has been handed over to a private group, we will end up losing it, as it is now not operating at capacity due to clients receiving little to no funding, therefore making the respite house unviable to continue operating into the future.”

- 2018 Carer Survey respondent

Continue to invest in carer wellbeing

Carers of people with disability under the age of 65 years were previously able to access respite under a range of ADHC and Commonwealth funded programs, however, nearly all of these programs have been subsumed by the NDIS. The DSS funded Commonwealth Carelink and Respite Centres (CRCCs), which currently broker respite for carers of over 65s and carers of under 65s not eligible for the NDIS, are the key exception.

However, CRCCs will soon be replaced by a smaller network of Regional Delivery Partners (RDP) under the ICSS which, among other functions, will broker emergency respite to carers across NSW. In addition, a small number of Carer Directed Packages (up to \$3,000) will be provided by RDPs to

⁸ Carers Australia (2017) *Improving access to aged residential respite care*, Retrieved from: <http://www.carersaustralia.com.au/storage/residential-respite-care-report.pdf>.

⁹ National Disability Services (2018) *State of the Disability Sector Report*, Retrieved from <https://www.nds.org.au/news/state-of-the-disability-sector-report-2018-now-available>.

prioritised carers for purposes including, but not limited to, respite. Most carers will not be eligible to access a package, and for those using it to purchase respite, \$3,000 will not go very far.

These are the only explicit opportunities to access respite under the ICSS model. The ICSS assumes that for the vast majority of carers, the NDIS and aged care systems sufficiently provide those they care for with planned respite and/or a respite effect. While this is true for many, the Carers NSW 2018 Carer Survey found that the majority of carers of people accessing the NDIS and aged care services were not able to have a break, attend to their own health needs or access employment as a result of these services.¹⁰ Further, more than one third of survey respondents who accessed respite services indicated that they would like more access to respite.¹¹

A range of other service types delivered locally by RDPs and nationally via the Carer Gateway – including carer coaching, carer counselling, peer support and education – are intended to prevent crisis and reduce the need for respite by building carers’ capacity and supporting their wellbeing.

While this promises to be the case for many carers, Carers NSW is concerned that there is no provision within the ICSS model to fund planned, regular respite for the large

numbers of carers who are not prioritised as in crisis but who could benefit from a break from their caring role. For carers unable to access regular replacement care through other systems, there is also nothing within ICSS to support them to access this in order to gain or maintain employment, or receive ongoing treatment for a health condition that may require multiple absences from home. Services for the person they care for may have this effect, but evidence suggests that carers’ needs are not consistently being taken into account.¹²

Carers NSW believes that all carers should be entitled to regular breaks and focus on their own wellbeing, and that flexible, affordable options for replacement care should be available to free up all carers to participate in paid employment and attend to their own health, as needed. We therefore urge the NSW Government to consider how this significant gap in funded respite may be addressed in NSW within the 2019-20 financial year and beyond.

“Before the NDIS, we accessed 31 days of respite per year under ADHC. In my son’s first plan NDIS did not fund any respite or community access type activities, so since the start of the NDIS funding in 2017 we have had no respite or break from caring for a very high needs individual with challenging behaviours.”

- 2018 Carer Survey respondent

¹⁰ Carers NSW (2018a)

¹¹ Ibid.

¹² Carers NSW (2018a), (2018b), (2018c)

3. HELP CARERS NAVIGATE COMPLEX SERVICE SYSTEMS

The NDIS, ICSS and aged care system have a strong focus on capacity building, aiming to prevent crises and reduce ongoing reliance on resource-intensive service types. As a result, the case management functions that were previously available to many families under ADHC programs have been replaced within the NDIS by a time-limited, lighter touch support coordination model designed to increase independence over time.

Many carers have reported to Carers NSW that the support connection and support coordination available to them has fallen short of their need, leading them to take on more of an administrative role than they have in the past. Indeed, 67% of respondents to the Carers NSW 2018 Carer survey who were caring for an NDIS participant reported that the time they spent organising support for the person they care for had increased in the past two years.¹³ For many carers, the increase in workload has been unsustainable for their own wellbeing.

At the same time, the shift towards individualisation in the disability and aged care sectors, and the national push for digitising services to increase reach and reduce cost, have led to a reduction in block funding for face to face, group based, capacity building activities targeting carers. The ILC is able to block fund such activities, but its rollout within NSW has been slower than anticipated.¹⁴ In addition, the ILC is disability focused and therefore not available to other cohorts, and carer specific support is not within scope.

Carers are not only facing complex new systems with a reduction in certain types of support; many are also dealing with multiple other service systems which they require support to navigate effectively. The reduction in case management support across the sector and the intended withdrawal of State disability advocacy funding following the NDIS transition will increase the urgent need many carers have for one-to-one, intensive support.

In the 2019-20 financial year, ongoing and additional capacity building funding tailored to carers is needed to fill this gap. Carers NSW recommends that the NSW Government:

Recommendations

- Maintain funding for carer capacity building programs (pp. 11-12)
- Establish case coordinator positions to support young carers (p. 12)

Maintain funding for carer capacity building programs

Some carer capacity building funding at the State level has not been directly affected by the closure of ADHC. For example, Carers NSW has maintained peak activities funding from FACS to deliver education and training to carers, and a number of the FACS funded CIP projects have a capacity building focus. Another program focused on building carer capacity that has not been in scope for the NDIS is the NSW Health funded Family and Carer Mental Health Program (FCMHP). Local health district (LHD) carer programs also deliver some carer capacity building support.

Carers NSW urges the NSW Government to continue funding these and similar carer capacity building programs at the State level, especially those addressing particular cohorts of carers. Groups

¹³ Carers NSW (2018a)

¹⁴ Portfolio Committee No. 2 – Health and Community Services Implementation of the National Disability Insurance Scheme and the Provision of Disability Services in New South Wales. (Uncorrected proof). Sydney, October 2018.

with specific needs, such as mental health carers, young carers, and parents of young children, may not receive a tailored service response under the ICSS model, as the mode and extent of outreach to specific target groups will be within the discretion of RDPs.

Establish case coordinator positions to support young carers

There are approximately 96,000 carers in NSW who are aged 25 years and under.¹⁵ While caring at a young age can provide young carers with a sense of pride and satisfaction as well as important life skills, young carers are more likely to experience a number of vulnerabilities when it comes to their own health and wellbeing, education, employment and social participation.¹⁶ In addition, young carers are often required to navigate complex service systems including the NDIS, My Aged Care, Centrelink for the person they care for, whilst also accessing services for their own needs. Consequently, many young carers have limited means or time to address their own needs and participate in economic and social life.

Carers NSW commends the NSW Government for refunding the Carers NSW Young Carer Program for another three years to provide information and support to young carers. Similarly, funding through the CIP to young carer focused projects including YC-Drive (delivered by Carers NSW) as well as the Deadly SIBS project (operated by Catholic Care Wollongong) address specific challenges that young carers encounter including barriers to obtaining a provisional driving license and increasing the engagement of Aboriginal young carers. We have also welcomed the opportunity to deliver one of the new Commonwealth funded Try, Test and Learn fund programs supporting young carers to access employment and education.

However, Carers NSW is conscious that under the ICSS no young carer specific services are mandated other than the Young Carer Bursary, which provides financial support to assist a small number of young carers to access education. Furthermore, while many young carer programs exist, as detailed above, none offer intensive, specialist one-to-one case coordination for young carers who are highly disadvantaged and need a trustworthy contact and advocate. Carers NSW recommends that the NSW Government fund one full-time equivalent staff member in each of the four RDPs in NSW (four in total) to provide this essential service to young carers.

Dana, 16, and Ellie, 12 care for their mother, Jill, who lives with a mental illness and has a number of complex chronic health conditions, and their brother, Steve, who experiences drug and alcohol addiction. The family are on a very low income as Jill is unable to work and Steve is unemployed. They have moved three times in the past six months and are at risk of losing their housing again. Dana and Ellie have missed a lot of school this year managing crisis situations and the stress from their housing and financial situations, and Jill's fluctuating health, is affecting their grades. They need someone who understands their situation to sit down with them regularly, check how they are doing, and help them put arrangements in place to secure their family's wellbeing.

¹⁵ ABS (2017)

¹⁶ ABS (2017); Hill, et al. (2016) *Carers and Social Inclusion, Carers and Social Inclusion*, Social Policy Research Centre, University of New South Wales, Sydney; Cass, B. et al. (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Social Policy Research Centre.

CONCLUSION

In light of the many ongoing changes to the carer support sector in NSW, Carers NSW urges the NSW Government to continue monitoring and addressing emerging service gaps by considering our Budget recommendations for the 2019-20 financial year. The NSW Government has a strong track record of supporting carers and continues to demonstrate that it takes its legislated obligations of carer recognition seriously.

Carers NSW looks forward to continuing to work with the NSW Government in championing carers, keeping our State in the business of carer support, and assisting carers to navigate complex service systems. The measures we have proposed will ensure that carers and the people they care for continue to have access to critical safety nets as NSW transitions to the NDIS, and soon, to the ICSS.