



No carer worse off

**Carers NSW Pre-Budget Submission
2018-19**

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in NSW and a member of the National Network of Carers Associations. Our focus is on improving the lives of carers.

Carers NSW is a not-for-profit registered charity and company limited by guarantee. It is governed by a Board of Directors in accordance with the Corporations Act 2001 and the Australian Charities and Not-for-profits Commission Act 2012.

Carers NSW vision is for an Australia that values and supports all carers, and its goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community and government.

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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. To replace the care they provide the NSW Government would have to spend around \$17 billion each year on formal care services. 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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INTRODUCTION

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) leading whole-of-government carer recognition and support nationally. In spite of the challenges presented by significant sector reforms at both Commonwealth and State levels, 2017 held a number of positive milestones for carers in NSW.

Following a statutory review in 2016, May 2017 saw the amended Act, including a considerably improved NSW Carers Charter, passed by both Houses of Parliament. Carers NSW is supportive of the changes, many of which were in line with our recommendations.¹

July 2017 marked the beginning of the last year of NDIS rollout in NSW, with nearly 44,000 people with disability already having approved NDIS plans,² and 70,000 more scheduled to transition within a twelve month period.³ Participant satisfaction in NSW remained high at 80 per cent,⁴ with the most recent research indicating that many carers were benefiting from the transition.⁵

The announcement of the Carers Investment Program by the Department of Family and Community Services (FACS) in August 2017 reflected the NSW Government's continuing commitment to support carers in line with the focus areas of the Strategy. Carers NSW welcomed this commitment, as well as the opportunity it provided our organisation to propose ten innovative, evidence-based carer projects for consideration.

Carers NSW commends the NSW Government on its ongoing support of carers, but wishes to highlight that carer recognition and support are currently at risk, particularly as NSW transitions to the NDIS. Carers NSW urges the NSW Government to address gaps that are leaving carers worse off, and consider its ongoing role in supporting carers into the future.

This Pre-Budget Submission focuses on four key areas that Carers NSW has identified as of the most importance to address for carers in the 2018-19 State Budget. These are:

1. Ongoing commitment to carers
2. Gaps in NDIS transition
3. Building carer resilience
4. Keeping carers engaged

Our recommendations, developed in consultation with our staff, carers and key partners and stakeholders, highlight what we believe are the most achievable and cost-effective ways in which the NSW Government can make practical gains for carers in the 2018-19 financial year. Carers NSW urges the NSW Government to seriously consider these recommendations and commit to ensuring that no carer is worse off in the 2018-19 State Budget.

SUMMARY OF RECOMMENDATIONS

Carers NSW recommends that the **NSW Government**:

- Continue to fund disability peak and advocacy organisations to provide individual support to people with disability, their families and carers as they navigate a changing service system (**Recommendation 9**).

Carers NSW recommends that the **NSW Premier**:

- Appoint a Minister of Disability, Ageing and Carers to oversee the implementation of the Act and Strategy, along with the *NSW Ageing Strategy 2016-2020* and *NSW Disability Inclusion Act 2014* (**Recommendation 4**).

Carers NSW recommends that the **NSW Treasury**:

- Replace the funding previously provided to LHDs by ADHC under the CCSP to enable the health system to continue to support former ADHC clients whose support needs will not be addressed by the NDIS (**Recommendation 5**).
- Redirect a portion of the funds previously allocated to ADHC for the delivery of early intervention services to LHDs for the 2018-2019 financial year to act as a safety net for families of children aged 0-6 who are awaiting ECEI access (**Recommendation 6**).

Carers NSW recommends that **Transport for NSW**:

- Expand the Community Transport Program to address gaps in community transport funding for carers in the transition to the NDIS (**Recommendation 10**).

Carers NSW recommends that the **NSW Department of Family and Community Services:**

- Invest a minimum of \$100,000 in leading the co-design of a *NSW Carers Strategy 2020-2025* (**Recommendation 1**).
- Invest a minimum of \$100,000 in leading a comprehensive promotional campaign to support the implementation of the amended Act (**Recommendation 2**).
- Maintain an Office for Carers dedicated to overseeing the full range of carer projects (**Recommendation 3**).
- Invest a minimum of \$50,000 to map changes to carer support services in NSW, with the purpose of identifying service gaps and reporting to the Minister on the impact of the NDIS transition on carers (**Recommendation 7**).
- Allocate \$800,000 toward NDIS transition support for ageing parent carers in 2018-2019 under the *NSW Carers Strategy 2014-2019* and/or *NSW Ageing Strategy 2016-2020* (**Recommendation 8**).
- Establish a grant program awarding small grants of \$500 to \$3,000 to carers to fund time-saving technology (**Recommendation 15**).

Carers NSW recommends that **NSW Health:**

- Invest \$250,000 to fund a Community Health Nurse and a specialised Occupational Therapist to pilot carer health checks and manual handling training to carers in one LHD (**Recommendation 11**).
- Invest \$25 million over four years to expand the mental health peer workforce as per the recommendations made by NCOSS (**Recommendation 12**) and identify specific carer peer mental health worker positions within the mental health peer workforce (**Recommendation 13**).

Carers NSW recommends that the **NSW Department of Industry, Skills and Regional Development:**

- Commit \$150,000 towards a scholarship scheme to assist carers to retrain or upskill when seeking to re-enter the workforce (**Recommendation 14**).

1. ONGOING COMMITMENT TO CARERS

1.1 NSW Carers Strategy

Carers NSW welcomes the Government's ongoing financial commitment to supporting carers, most recently reflected in the announcement of \$5.6 million over three years for carer focused projects via the NSW Carers Investment Program. While the objectives of this funding align strongly with the *NSW Carers Strategy 2014-2019* (the Strategy), Carers NSW is conscious that funded projects will outlast the Strategy, which is due to end in 2019. In order to secure ongoing strategic direction for carer focused projects within NSW, the NSW Government must invest in the co-design of a new Strategy as part of the 2018-19 State Budget, laying the foundation for a new round of project grants to take effect from 2020.

Recommendation 1: Carers NSW recommends that the NSW Department of Family and Community Services invest a minimum of \$100,000 in leading the co-design of a *NSW Carers Strategy 2020-2025*.

1.2 Carers (Recognition) Act

Carers NSW also urges FACS to invest generously in promoting and implementing the amended *NSW Carers (Recognition) Act 2010* (the Act) and accompanying *NSW Carers Charter* (the Charter). Timely, targeted promotion will be essential to ensure that the Act achieves its objective of carer recognition, which Carers NSW research and consultation indicates is still low within the community, and within public sector agencies.⁶ In order to raise awareness of the Act and Charter among carers, service providers and employers, FACS should replicate the 2010 targeted information and implementation campaign. Carers NSW also believes it would be beneficial for FACS to develop materials to encourage Government funded organisations to implement the Charter with their clients and employees, although they are currently not obligated to under the Act.

Recommendation 2: Carers NSW recommends that the NSW Department of Family and Community Services invest a minimum of \$100,000 in leading a comprehensive promotional campaign to support the implementation of the amended Act.

1.3 Dedicated carer team

A dedicated team will be required within FACS to manage ongoing carer project funding, the co-design of the *NSW Carers Strategy 2020-2025* and lead the information campaign regarding the implementation of the Act. In the midst of ongoing restructures within FACS, Carers NSW urges the NSW Government to ensure that a dedicated carer team is maintained in order to properly oversee these endeavours.

Recommendation 3: Carers NSW recommends that the NSW Department of Family and Community Services maintain an Office for Carers dedicating to overseeing the full range of carer projects.

1.4 Ministerial portfolio

Currently carers are not explicitly mentioned in the relevant ministerial portfolio held by The Hon. Ray Williams MP, Minister for Multiculturalism and Disability Services, nor in that of the Hon. Tanya Davies MP, Minister for Mental Health, Women and Ageing. Carers NSW believes that carers should be explicitly mentioned to remain on the Government's agenda, in line with the whole-of-government focus of the Strategy and the obligations on public sector agencies under the Act. As ageing and disability policy are strongly interconnected with carer policy, and both areas have their own state-based strategic frameworks, Carers NSW believes that all three areas should be the responsibility of one Minister.

Recommendation 4: Carers NSW recommends that the NSW Premier appoint a Minister of Disability, Ageing and Carers to oversee the implementation of the Act and Strategy, along with the *NSW Ageing Strategy 2016-2020* and *NSW Disability Inclusion Act 2014*.

2. GAPS IN NDIS TRANSITION

2.1 ADHC clients ineligible for the NDIS

A dedicated ministerial portfolio and departmental team will be particularly important to ensure the ongoing recognition and support of carers as the NDIS reaches full scheme in July 2018. Many NSW residents with disability and their carers will continue to enter the NDIS for the first time following this date, including those who previously received no support, or support from sources other than ADHC, and those who find themselves facing a new injury or diagnosis. Further, a number of NGOs and health system representatives have indicated to Carers NSW that many clients of the Community Care Supports Program (CCSP), a non-defined ADHC program, will not be eligible for NDIS support, but will have ongoing needs for direct support which will not be provided by the ADHC continuity of support response (the Pathways Project) or the Information, Linkages and Capacity Building (ILC) grants.

Lorraine cares for her husband Errol*, who is in his early 60s and has a chronic illness that greatly affects his physical functioning. They previously received in-home support services, transport and respite services, however as he is not eligible for the NDIS, and these supports are being withdrawn at a state level, there is nothing left for Errol, increasing the pressure on Lorraine.*

If these former ADHC clients, who typically belong to vulnerable population groups and have complex needs associated with episodic or chronic health conditions, are not adequately supported, they risk ending up in inappropriate care situations, such as lengthy hospital stays or within unsustainable informal care arrangements, affecting carer health and wellbeing. These clients were previously supported by organisations including local health districts (LHDs) with CCSP funding from ADHC. The withdrawal of this ADHC funding

threatens to make ongoing intensive support to these clients unsustainable unless compensatory measures take place.

Recommendation 5: Carers NSW recommends that the NSW Treasury replace the funding previously provided to LHDs by ADHC under the CCSP to enable the health system to continue to support former ADHC clients whose support needs will not be addressed by the NDIS.

2.2 Early childhood intervention

Since the Commonwealth funded program Better Start for Children with Disability closed registrations in NSW on 1 August 2017, Carers NSW has been contacted by more than thirty carers and service providers representing carers highlighting outrageously long waiting times for accessing Early Childhood Early Intervention (ECEI) partners. Some have been told that they will not be able to access early intervention support from the NDIS for up to two years. These kinds of waits are simply unacceptable for children who require immediate early intervention to reduce the impact of their diagnosis and subsequently the future support costs to their families and the service system.

Consultation with our colleagues in the other States and Territories indicate that this is a particular problem in NSW, indicating that it is a feature of the NSW rollout arrangements. Even though ADHC is winding up, the NSW Government has a responsibility to ensure that families continue to have access to timely early intervention support until ECEI support becomes available.

James is three years old. His family has been waiting indefinitely to meet with their local ECEI partner, and in the meantime have lost access to his ADHC funded social skills groups, occupational therapy and weekly speech therapy due to the NDIS transition. In June they were told by their ECEI partner that they would likely be waiting until Christmas. In the meantime, the loss of ADHC support has caused a downward spiral in James' behaviour, severely impacting his family's routine and wellbeing.

Recommendation 6: Carers NSW recommends that the NSW Treasury redirect a portion of the funds previously allocated to ADHC for the delivery of early intervention services to LHDs for the 2018-2019 financial year to act as a safety net for families of children aged 0-6 who are awaiting ECEI access.

2.3 Carer support services

Carers NSW is supportive of the NDIS in principle, however we are also highly concerned about the many gaps emerging that directly impact carer supports. Most carer specific programs funded by the NSW and Commonwealth governments are in scope for transition to the NDIS, despite carers not being the focus of NDIS plans. Many carers stand to benefit indirectly from the supports provided to those they care for, however the fact remains that

many carers will not, either because the person they care for will not be eligible for support, or because no carer-specific assessment or support is mandated within the NDIS.

As a result of ongoing advocacy from the carer support sector, the Department of Social Services is in the process of developing an Integrated Carer Support Service (ICSS) in consultation with carers and the sector. While this system promises to fill some of the gaps created by NDIS transition and introduce new innovative forms of support for carers, it does not yet have ministerial commitment or full funding, and many gaps remain.

A number of valuable ADHC funded programs where carers are either the direct client, or whose needs are addressed in addition to those of the person with disability via assessment and support, are already disappearing as the NDIS rolls out in NSW. Some of these service types are able to be continued or replaced under NDIS plans such as future/succession planning, certain forms of respite (under a different name), supported accommodation, behaviour support, and certain types of one-off purchases directly related to the care recipient's disability. However, a number of support types remain out of scope for both the NDIS, the ILC and the ICSS, including:

- Seed funding, training and support for carer support groups
- Support coordination working with the carer as client and prioritising their own needs
- Tailored support for ageing parent carers
- Funding packages that carers can use to meet their own needs
- One off purchases to benefit the carer and their household that are not disability specific
- Recreational and educational opportunities integrating peer support and respite components (including events, retreats)
- Respite supports that focus on the carer's need for a break
- Case management that provides ongoing individual support to a person with disability and their family and carers

The disappearance of these support types threatens to severely disadvantage carers. In line with the Act, the NSW Government is responsible for ensuring that carers continue to be recognised and supported in NSW.

Recommendation 7: Carers NSW recommends that the NSW Department of Family and Community Services invest a minimum of \$50,000 to map changes to carer support services in NSW, with the purpose of identifying service gaps and reporting to the Minister on the impact of the NDIS transition on carers.

2.4 Ageing parent carers

Carers NSW is particularly concerned about ageing parent carers, who are a vulnerable group that struggle to access services, especially via digital platforms.⁷ Originally funded by ADHC in 2008 under the *NSW Carers Action Plan 2007-2012* (the predecessor of the Strategy) Carers NSW, along with a range of other service providers, has until recently the Older Parent Carer Support Coordination (OPC) Program in three areas of NSW. The OPC Program provides case management and transition planning to ageing parent carers of an adult son or daughter with disability, but is currently phasing out. Carers NSW has also been informed that ADHC's continuity of support response (the Pathways Project) does not

include OPC program clients, despite them being clients of ADHC funded services, in direct contravention of the bilateral agreement specifications around continuity of support. We have previously raised this with the Premier and Minister for Disability Services.

Carers NSW has also recently reinvested some program surplus, with the support of FACS, into a dedicated NDIS transition project targeted at our transitioning OPC clients. This support has been very well received, and has highlighted to Carers NSW staff the extent of support needed by this group, which will no longer be provided once this project ends, especially as many of our transitioning clients are not being allocated support coordination funding as part of the care recipient's NDIS plan.

Marta is a CALD carer in her 60s and cares for her adult son Andre, who has an intellectual disability. Aside from her husband, Marta has no other family in Australia to help care for Andre.

Since 2011 Carers NSW has assisted Marta with negotiating the public housing system, applications for private rentals; coordinating different service providers for Andre, in an attempt to find suitable services, including respite; alerted Marta to My Aged Care and assisted with requesting assessment; provided information and support for suitable transport for Andre; acted as advocate on Marta's behalf with Centrelink; helped with representations to the Minister for intervention on the family's behalf; provided counselling and support and, provided help and guidance transitioning Andre to the NDIS.

Andre received his NDIS plan in August this year, and Marta is no longer eligible for any support at all through the Carers NSW OPC program. Marta did not receive support coordination in her son's NDIS package. Andre's service providers will only provide information and support if it can be paid for under an NDIS line item. However, there is no specific support available for Marta in her caring role, increasing her stress and anxiety.

Carers NSW believes that ageing parent carers must continue to be a priority for FACS, given that they are losing support in the transition to the NDIS and are not covered by ADHC's continuity of support program. As the OPC Program was initially funded under a state-based strategic framework, Carers NSW proposes that the carers and/or ageing strategies would be appropriate frameworks for providing project based funding to support this vulnerable cohort into the future.

Recommendation 8: Carers NSW recommends that the NSW Department of Family and Community Services allocate \$800,000 toward NDIS transition support for ageing parent carers in 2018-2019 under the *NSW Carers Strategy 2014-2019* and/or *NSW Ageing Strategy 2016-2020*.

2.5 Disability advocacy

Many carers inform us that they rely on specialist disability peak and advocacy organisations across NSW for reliable information about the condition of the person they care for and support in accessing services. The removal of this funding when ADHC closes in July 2018 is causing many carers great distress, as it is evident that much specialist knowledge and familiar, grassroots support will be lost to families at the time they need it most.

Carers NSW urges the NSW Government to respond to the requests of the Disability Advocacy Alliance and NSW Council for Social Service (NCOSS) to restore this funding. ILC and the National Disability Advocacy Program (NDAP) only offer limited support, and Carers NSW believes that the NSW Government should retain responsibility for supporting its residents to interact with state funded service systems such as transport, social housing and health, where, as disability advocacy organisation inform us, most of their work is done.

Jenny cares for her son Adam who has Down Syndrome. She said: "I have found the support of the Down Syndrome Association of NSW, IDEAS and NSW Council for Intellectual Disability invaluable, as with Family Advocacy. They have been a source of practical information and a way to connect with the wider community. Also they provide inspiration and ideas through lots of positive stories. Lastly they are an important voice for us all."

Recommendation 9: Carers NSW recommends that the NSW Government continue to fund disability peak and advocacy organisations to provide individual support to people with disability, their families and carers as they navigate a changing service system.

2.6 Community transport

Nearly one in six people with disability in NSW are not able to use any form of public transport,⁸ due to factors such as physical inaccessibility and poor wayfinding. Consequently, the majority of people with disability rely on informal carers or family members to meet their transport needs.⁹ However, approximately 14 per cent of people with disability utilise formal service providers, such as community transport, to meet their transport needs.¹⁰ Community transport enables many people with disability to travel independently, freeing up their carers to pursue other activities such as employment or education rather than be regularly required to personally transport, or accompany, the person they care for.

However, individualised funding packages within the disability and aged care sectors is changing the way community transport services are funded by absorbing previously available block funding. Carers NSW has heard from a number of carers that the transport funding component of the participant's NDIS packages is severely underfunded. As result, many carers are required to bear the costs of travel on community transport. In addition, there are many more people with disability who will be ineligible for an NDIS package altogether.

Block funding also previously enabled carers to accompany the person they care for either a small fee or at no cost. Consequently, many carers must now pay full fees to accompany the person they care for, adding to the already high expenses associated with their caring role. Whilst Commonwealth Home Support Program (CHSP) funding continues to subsidise carers accompanying a person who is over 65 of age, Carers NSW is concerned about carers who do not qualify for community transport subsidies.

Given the higher average price per trip for community transport (compared to public transport), particularly in rural and regional areas, carers may limit spending in other areas such as their own medication needs or limit transport altogether. There are flow on effects to the socioeconomic participation and the social isolation of people with disability and their carers.

Recommendation 10: Carers NSW recommends that Transport for NSW expand the Community Transport Program to address gaps in community transport funding for carers in the transition to the NDIS.

3. BUILDING CARER RESILIENCE

3.1 Carer health and wellbeing

Carers have consistently lower physical and psychological health and wellbeing compared to their non-caring counterparts.¹¹ One Australian study found that carers were more likely to suffer from a chronic condition such as asthma or diabetes least one chronic health condition when compared to the rest of the community, and were more likely to report risk factors including high blood pressure and high cholesterol, which can be exacerbated by the caring role.¹² Similarly, a quarter of all Australian carers experience high or very high levels of psychological distress, and are therefore highly likely to have a moderate to severe mental disorder.¹³ By comparison, around one in ten Australians experience high to very high levels of distress, with the vast majority experiencing low levels of distress.¹⁴

The determinants of carers' health and wellbeing are complex and in many circumstances are linked to the stressors of the caring role. In particular, carers with especially time-consuming caring roles, those lacking informal support networks and those who are financially disadvantaged are more likely to have worse health. This may be exacerbated by the fact that carers commonly neglect their own health, putting the needs of the person they care for ahead of their own.¹⁵ The health implications of providing care continue even after the caring role ends. Thus the emotional distress and physical injuries incurred during the caring role are likely to persist for many years amongst former carers.

Despite the high incidence and known causes of poor health and wellbeing amongst carers there are currently few services specifically targeted at carers' own health needs in NSW. Carer programs across LHDs undertake great work in raising awareness of carers and promoting carer participation however they are not resourced to address carers' physical

and emotional needs. NSW Health has a key role to play in proactively addressing carers physical and mental health needs in order to address ongoing health inequities.

3.2 Carer health checks and manual handling training

Free carer health checks are routinely delivered in a range of settings in the UK, including in the home and at pharmacies, community care centres, sports centres and GP practices. Nurses and other health workers conduct assessments of a carer's physical health including BMI, blood pressure, cholesterol and blood sugar as well as mental health assessments.¹⁶ Evaluation data indicates that health checks led to sustained self-care and healthier behaviours for many carers.¹⁷ Carers have stated that they provide an opportunity to attend to their own health needs, made them aware of health issues and motivated them followed up with referral to specialist treatment.¹⁸ Carers also identified benefits to their psychological wellbeing and recognition of the demands of their caring role.¹⁹

Carers NSW recommends that a similar approach be piloted in one NSW LHD in 2018-2019 to determine its suitability for statewide delivery. Carers NSW believes that Community Health Nurses are best placed to conduct the health checks, working closely with other health professionals in order to identify carers through existing clients of services such as the Chronic Disease Management Program (CDMP), the Family and Mental Health Carer Program and the Grief and Loss Service. In addition to the physical and psychological assessments, carer health checks would also provide an opportunity for Community Health Nurses to refer carers to existing supports and services.

This program differs from the NSW Health *Get Healthy Information and Coaching Service* and other community or workplace based health check programs promoted in the Strategy due to its carer-specific design, flexibility and comprehensive nature. The *Get Healthy Information and Coaching Service* is a telephone-based service and is unable to assess a person's blood pressure, BMI, cholesterol or blood sugar. Thus this service is more suited to people who are already aware of existing chronic health conditions, rather than identifying and treating such conditions. Furthermore, carers who are not in the workforce may not benefit from workplace health programs, while pharmacists are often limited to assessing a patient's risk factors and referring them onwards for confirmation from a GP.

In addition to carer health checks component, Carers NSW recommends that the pilot mentioned above incorporate a component which focuses on manual handling training to prevent physical injuries that carers commonly sustain in their caring role. Carers have identified this as a need in health check programs in the UK.²⁰

At least one third of all people with a reported disability in NSW have a profound or severe core activity limitation.²¹ People with a profound or severe core activity limitation invariably rely on informal carers for their self-care (80 per cent) and mobility needs (89 per cent).²² Such tasks often require the carer to manually manoeuvre the person by using lifting, carrying, pulling, pushing, or holding actions. Data also shows that home modifications such as grab rails or modifications to the toilet or bath are less common in households where there are others living there.²³

Given the many manual tasks that carers are required to perform on a daily basis, combined with a lack of home modifications and insufficient information on proper manual handling

procedures, it is unsurprising that carers commonly incur injuries, particularly back injuries.²⁴ One Australian study found that 43 per cent of carers indicated that they had an injury that had been caused by their caring role.²⁵ The same study showed that such injuries were worsened by continuing to care.²⁶ Inappropriate manual handling procedures not only expose the carer to the risk of injury but the person being cared for as well. Ultimately, such injuries may prevent a carer from being able to continue to provide care, relinquishing the person they care for into a residential facility.²⁷

Back problems incur a significant economic burden. Based on calculations made by Deloitte Access Economics, Arthritis and Osteoporosis Victoria estimated that back problems alone accounted for \$1,626 per person in terms of direct healthcare costs in 2012.²⁸ Without accounting for health inflation the annual healthcare cost of back problems alone amongst carers in NSW is at minimum \$208 million.²⁹ However, considering that chronic back pain is also associated with high psychological distress amongst carers,³⁰ these estimates significantly underestimate the economic and social cost of chronic back problems and pain. Furthermore, the cost of relinquishing a person to a formal care facility also far exceeds such estimates. For example, in 2015-16 New South Wales spending on residential aged care alone was \$3.84 billion. Per person this amounts to \$3,062 annually compared to \$968 in home care and support.³¹

In many cases, the injuries that carers sustain could be prevented altogether or lessened through the use of appropriate manual handling procedures as well as assistance technology installed within the home. While equipment such as hoists can be installed within the home, many carers are not provided with a prescription from a health professional. For those whose house has been assessed such assessments may be too infrequent to meet the manual handling demands of the care relationship particularly where the person has a degenerative or progressive condition combined with the ageing of the carer.³² However, the most common barrier to utilising such equipment is the ability to purchase it.³³ For example, a study of families with children with cerebral palsy calculated the median out-of-pocket expense for home modifications to the value of \$23,000 during the first six years of a child's life, a cost which is prohibitive to many carers on a low income.³⁴ While some carers will be able to access funding for home modifications under NDIS and Home Care packages, many others will not.

Regardless of whether a carer has assistive equipment installed within the home, appropriate manual handling training is essential.³⁵ Carers often express to us about their need for manual handling training. This is confirmed by research indicating that such training is lacking within the community.³⁶ Research also shows that for manual handling training to be effective it must be individualised, ideally provided within the home of the carer on an ongoing basis to address changing care needs over time.³⁷ Written materials alone are shown to have a limited impact on a carer's use of appropriate manual handling procedures.³⁸

Carers NSW envisages significant savings to the health budget as a result of such a holistic program. Identifying and treating physical and mental health conditions are likely to improve carer wellbeing overall, reducing the likelihood of chronic conditions developing and their associated complications which require extensive medical intervention or hospitalisation. Adequately equipping carers with the manual handling skills needed to protect their health and that of the person they care for is similarly likely to reduce preventable injuries and their associated sequelae.³⁹ When carers have their health adequately supported, they are more likely to sustain their caring role, ultimately lowering the likelihood of relinquishment to care

facilities.⁴⁰ Similarly, improved health and wellbeing of carers may also enable them to remain in paid work for longer.

Recommendation 11: Carers NSW recommends that NSW Health invest \$250,000 to fund a Community Health Nurse and a specialised Occupational Therapist to pilot carer health checks carer health checks and manual handling training to carers in one LHD.

3.3 Mental health carers

It has been estimated that the annual cost for the Australian Government to replace what mental health carers do with formal support services would be \$13.2 billion.⁴¹ Carers NSW believes that governments need to support mental health carers who are contributing significantly to our community with little recognition, and often at a cost to their own wellbeing. We were pleased to see an increase in funding of the Family and Carer Mental Health Program in the 2017-18 NSW Budget, however, findings from the Carers NSW 2016 Carer Survey (the Survey) indicate that further support is needed.

The Survey asked the nearly 2,000 carers who responded whether they felt recognised and valued by their community.⁴² Just over one quarter of all carers agreed that they were recognised, and almost double that amount disagreed.⁴³ Carers of people with a mental health condition were more likely to disagree that they were recognised.⁴⁴

The NSW Mental Health Commission recently consulted with carers from across NSW, and found that as a priority carers “need better, more explicit education and resources from the outset’ to better equip carers in their caring role” (p.5).⁴⁵ They also found that mental health services need to be better educated about the role and rights of carers, and that this education should be delivered by carers themselves.⁴⁶

Carers NSW believes that carer peer workers have a key role to play in supporting and educating carers as well as creating a more carer-friendly mental health service culture. Carers NSW has previously provided evidence on the value of carer peer workers in delivering these goals, and advocated for a strengthened mental health peer workforce.⁴⁷ We have also formally endorsed the NCOSS 2018-19 pre-budget submission and wish to express our support for their recommendation that \$25 million be invested over four years to expand the mental health peer workforce and support people at specific ‘pressure points’ in the mental healthcare system.⁴⁸

Recommendation 12: Carers NSW supports NCOSS in its recommendation for NSW Health to invest \$25 million over four years to expand the mental health peer workforce.

Recommendation 13: Carers NSW recommends that NSW Health also identify specific carer peer mental health worker positions within the mental health peer workforce.

4. KEEPING CARERS ENGAGED

4.1 Support to re-enter the workforce

In NSW approximately 45 per cent of carers, and 60 per cent of primary carers, are not in the labour force.⁴⁹ Many carers remain outside the workforce for some time, acquiring significant gaps in their resumes, and making seeking to return to work following the end of their caring role a daunting prospect.⁵⁰ Furthermore, mature-age workers are well known to experience challenges in the workforce, even without career interruptions.⁵¹ However, many carers experience disadvantage due to their age, coupled with their out-dated skills.

As demonstrated by the SkillsLink2Work program funded by FACS as part of the Strategy, carers often possess many skills which are essential in the workplace including organisation, budgeting and managing money, multitasking, administration, problem solving and managing difficult situations. While this tool contributes towards enabling carers to express the specific skills they have acquired in their caring role into employment-related terms for resumes, there is a need for more targeted employment support to assist carers re-enter the workforce.

As part of the *NSW Ageing Strategy 2016-2020* (the Ageing Strategy) the NSW Government has committed to respond to the challenges that older people, including carers, face in the workforce.⁵² The Ageing Strategy states that the Government will “provide access to retraining opportunities targeted at older people with lower qualifications or in manual occupations, and people who have been in and out of the workforce, including carers” (page 25). Both the ageing and carers strategies state that the Smart and Skilled Program (amongst others) seeks to address some of the challenges carers face in the workforce. However, Carers NSW would like to note that the Smart and Skilled Program is primarily targeted at younger cohorts and not all carers wish to acquire a TAFE qualification.

To address this gap, Carers NSW recommends that the NSW Government invest \$150,000 towards skills scholarships for carers who require qualifications to upskill or retrain to assist them in re-entering the workforce. Carers NSW proposes the introduction of;

- 20 scholarships for community education courses at \$1,000 each
- 10 scholarships for vocational education (including TAFE and private colleges) at \$5,000 each
- 5 scholarships for university degrees at \$10,000 each

Additional funds would be required for administration of the scholarships.

Eligibility would be based on a carer’s ability to demonstrate how their current or previous caring role has impacted on their employment and their career, ultimately requiring new qualifications to assist them in achieving their career goals. Carers would be required to demonstrate how they would benefit from receiving such a scholarship and show how it will facilitate future employment opportunities in their chosen career path. Carers NSW recommends that eligibility for such grants be extended to former carers, not just those currently caring, as former carers to facilitate their re-entry into the workforce.

A recent evaluation of the Young Carer Bursary Program administered by Carers Australia found that the bursaries have contributed towards the reduction of financial pressure and social isolation and has supported young carers to remain in education despite a high caring load.⁵³

Recommendation 14: Carers NSW recommends that the NSW Department of Industry, Skills and Regional Development commit \$150,000 towards a scholarship scheme to assist carers to retrain or upskill when seeking to re-enter the workforce.

4.2 Competitive grants

Nearly half of all primary carers in NSW spend more than 40 hours a week on care and care related tasks for a friend or family member.⁵⁴ While the majority of this time involves providing personal care and emotional support to the person they care for, a considerable amount of a carer's time and resources are taken up with domestic tasks such as preparing meals, cleaning or maintaining the property and other household chores.

Given that a third of carers live in low income households,⁵⁵ many lack the disposable income to invest in household items and technology that could reduce the time taken to perform household tasks such as a washing machine, dryer, dishwasher, tablet or personal computer. Time saving technologies could reduce the amount of time spent on caring related tasks, freeing carers up to take time for self-care, paid employment or personal development through study and career development.

In the UK, carers can receive personalised budgets which can fund technologies and activities that assist them with tasks related to caring (washing machine), reduce social isolation (laptop or tablet) or promote wellbeing (gym membership). Carers NSW currently delivers the Older Parent Carer Support Coordination program which has for several years offered similar grants to enable ageing parent carers to purchase household items and technologies that make caring tasks easier or faster to perform. Carers have been supported to purchase refrigerators, washing machines and tablets, or an internet connection – essential for accessing online government services such as the NDIS, My Aged Care or the MyGov portal.

Carers NSW recommends that the NSW Department of Family and Community Services fund small grants for one-off purchases of time saving technology, such as a dishwasher, slow cooker or robovac. Carers NSW believes that this low-cost, individualised intervention would assist carers to fulfil domestic responsibilities associated with their caring roles, freeing them up to engage in other activities, essential to their health and wellbeing, educational attainment and/or workforce participation.

Recommendation 15: Carers NSW recommends that the NSW Department of Family and Community Services establish a grant program awarding small grants of \$500 to \$3,000 to carers to fund time-saving technology.

CONCLUSION

Carers NSW would like to thank the NSW Government for its ongoing commitment to carers and for this opportunity to contribute to the future direction of our state. Our submission has identified areas which require the urgent attention of the NSW Government in order to ensure that no carer is worse off, as well as opportunities for the Government to prioritise carers in order to sustain caring into the future. We urge the NSW Government to consider our recommendations as it prepares to deliver the 2018-19 Budget.

Carers NSW looks forward to continuing to work closely with the NSW Government to achieve our vision – that all carers are recognised, valued and supported by the community and by governments.

* All names used in case studies have been changed for privacy purposes

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