

# Making it Happen for Carers

**Carers NSW 2016-17 pre-budget submission**

## About Carers NSW

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 our 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.

[www.carersnsw.org.au](http://www.carersnsw.org.au)

<https://twitter.com/CarersNSW>

## 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 850,000 carers, and to replace them the NSW Government would have to spend around \$17 billion each year. 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

In August 2015 we heard new evidence from Deloitte Access Economics that demand for family and friend carers is at an all-time high, and set to increase.<sup>1</sup> *The economic value of informal care in Australia in 2015* estimated that Australia's carers will provide 1.9 billion hours of care in 2015, and if we paid for that care it would cost us \$60.3 billion, or 3.8 per cent of our Gross Domestic Product. Using the same economic modelling, Carers NSW has made a conservative estimate that the replacement cost for carers in NSW is \$17.7 billion.

The Deloitte Access Economics report provides compelling evidence that any investment in supporting unpaid carers is more than compensated for by the contribution they make to our economy, a fact which is increasingly being recognised by Federal and State governments. Carers NSW urges the NSW Government to keep these findings in mind when developing and delivering the 2016-17 State Budget.

Carers contribute to the health, wellbeing, inclusion and participation of thousands of people living in NSW who have a disability, long-term health condition or who are ageing. The Honourable John Ajaka, MLC, Minister for Disability Services and Ageing, acknowledged the immense contribution that carers make at this year's NSW Carers Awards, held during Carers Week 2015, stating that:

*‘Without carers, many people would not be able to enjoy independence and participate fully in their communities.’*

The NSW Government has articulated recognition and support for carers through a range of policies and pieces of legislation in recent years. The *NSW Carers Strategy 2014-2019* is the current centrepiece of NSW carer policy and presents a strong, strategic vision for carers in our communities that is a blueprint for widespread reform.

Despite high-level recognition of the essential contribution carers make to our state, carers in NSW continue to be socially and economically marginalised. It is well documented that when Australians take on a caring role they are likely to face significant financial hardship, as well as challenges to their mental and physical health. The latest edition of *What Makes Us Happy*, the report on the Australian Unity Wellbeing Index, has re-iterated previous disturbing findings that carers have the lowest wellbeing of any group, including the unemployed and homeless.<sup>2</sup>

Furthermore, whilst carers in NSW consistently emphasise positive aspects of their caring role, our most recent research has revealed that most carers believe that recognition and acknowledgment of carers by services and the wider community is low.<sup>3</sup>

It is clear that we are not yet 'making it happen' for carers in NSW, and we have more work to do to ensure that the frameworks, documents and policies we have developed to improve carer recognition are resulting in tangible benefits for carers.

In order to improve outcomes for carers it is essential that NSW Government makes a meaningful investment in carers across a range of services and sectors. Investing in carers will mean that more carers will be able to find the information and support they need to provide assistance to their loved ones. Carers who are recognised, included and valued are more likely to maintain their health, keep or find employment and use their skills to benefit their loved ones and the wider community. Carer recognition and inclusion are also critical to the success of the widespread sector reforms being championed by the NSW Government.

This submission will focus on 5 key areas which Carers NSW has identified as offering the greatest opportunities for the NSW Government to make practical gains for carers. These are:

1. Delivering the *NSW Carers Strategy 2014-19*
2. Carer inclusive mental health services
3. Carer focussed health system
4. Transition to the NDIS
5. Carer rights

Our 20 recommendations are based on advice received from carers, Carers NSW staff and our key partners and stakeholders, and the strategies we have identified as being both achievable and cost effective. Carers NSW encourages the NSW Government to take these recommendations on board- to deliver on good intentions, implement change, and make it happen for carers in NSW.



Elena Katrakis  
CEO  
Carers NSW  
November 2015

## Summary of Recommendations

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

1. Continue to support and invest in the *NSW Carers Strategy 2014 -2019* in order to maximise outcomes for carers.

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

2. Continue to fund community outreach initiatives aimed at reaching hidden carers.

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

3. Continue to fund training for staff of specialist and mainstream service providers in reaching hidden carers, including hidden young carers.

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

4. Continue to fund the expansion of carer peer support programs in NSW.

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

5. Establish an *Aboriginal Carer Network* to connect and better resource Aboriginal carers, organisations and community groups across NSW.

**Carers NSW recommends that NSW Health:**

6. Ensure that adequate resources are available to inform and educate carers about the changes to the *Mental Health Act 2007* and their rights under the Act.

**Carers NSW recommends that NSW Health:**

7. Invest in a pilot carer peer worker study to build the evidence base on carer peer workers in mental health services in NSW.

**Carers NSW recommends that NSW Health:**

8. Provide ongoing, sustainable funding to progressively roll out the TOP 5 initiative across NSW.

**Carers NSW recommends that NSW Health:**

9. Invest in appropriate on-site accommodation designed for carers supporting patients in hospital.

**Carers NSW recommends that NSW Health:**

10. Increase funding to the *NSW Chronic Disease Management Program* to improve support for carers.

**Carers NSW recommends that NSW Health:**

11. Work with the Commonwealth to ensure that there are no funding gaps for people on Commonwealth Home Care Packages who require aids and equipment.

**Carers NSW recommends that NSW Health:**

12. Establish clear funding arrangements between NSW Health and disability services which will promote appropriate, timely care for people with disability and carers.

**Carers NSW recommends that NSW Health:**

13. Measure and report on outcomes for carers who are accessing NSW Health services.

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

14. Work with the Commonwealth to ensure that there are no service gaps for people with disability and their carers in the lead up to the NDIS and after full rollout.

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

15. Ensure that there remains a provider of last resort for people with complex needs.

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

16. Continue to provide and improve information, communication and capacity building opportunities for carers about the NDIS in NSW.

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

17. Prioritise carer awareness training for service providers in the allocation of funding for the Disability Sector Transition Fund.

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

18. Expand funding within existing services and programs, to enable more families to obtain evidence of type, level and impact of disability to assist them with applying for the NDIS.

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

19. Commission a review to identify how legislation, policy and systems in NSW can be improved to facilitate direct employment.

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

20. Undertake the review of the *NSW Carers (Recognition) Act 2010*.

# 1. Delivering the *NSW Carers Strategy 2014-2019*

The *NSW Carers Strategy 2014-2019* (the Strategy) commits the NSW Government to improving the position of carers in NSW, and provides an overview of projects which will support all carers across NSW to be healthy and live well.

## 1.1 Investing in the Strategy

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

1. Continue to support and invest in the *NSW Carers Strategy 2014 -2019* in order to maximise outcomes for carers.

Carers NSW is a key partner of the NSW Government in the Strategy, and is actively involved in the ongoing development and delivery of a range of projects within the Strategy. We have already seen the Strategy deliver positive outcomes for carers, including the launch of the 'Who Carers' app for young carers, which provides a platform for young carers to share their stories and access helpful information about accessing support for their caring role.

The collaborative approach taken by the NSW Government in the development and implementation of the Strategy has usefully drawn upon collective resources to drive innovation in the carer support sphere. However this approach can also restrict the potential within the Strategy to genuinely make a difference to carers' lives. We need a real investment from the NSW Government to ensure that the initiatives developed through the Strategy have the best chance of being effective.

Some specific examples of project areas which would benefit from an increased investment are considered below.

## 1.2 Reaching more hidden carers

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

2. Continue to fund community outreach initiatives aimed at reaching hidden carers.

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

3. Continue to fund training for staff of specialist and mainstream service providers in reaching hidden carers, including hidden young carers.

Improving information and service access for carers (Focus Areas 2 and 3) and increasing the engagement of carers by service providers (Focus Area 4) are key pillars of the Strategy.

Identifying 'hidden' carers will be critical in achieving these objectives. Hidden carers are carers who either do not think of themselves as a carer, do not disclose to others that they are a carer or are not known as a carer to services or agencies. This means they are unlikely to be counted in statistics about carers and may not know about or receive support.<sup>4</sup>

Certain groups of carers are particularly likely to be hidden, including Aboriginal carers, CALD carers, young carers (under 25), older carers (65+) and lesbian, gay, bisexual, transgender and intersex (LGBTI) carers. Common reasons that carers remain hidden include cultural expectations of caring as a duty, negative experiences with the service system, and limited time to seek support due of the demands of the caring role.<sup>5</sup>

Attempts to inform, support and engage carers will have a limited reach if they do not involve efforts to identify hidden carers. There are many ways to reach out to hidden carers. For example, providers of carer supports can identify hidden carers through targeted community outreach activities among priority population groups. Staff of specialist and mainstream service providers who regularly work with those groups can also be key players, recognising situations where there may be hidden carers and providing timely referral. Information and training about identifying hidden carers may be required for this to work.

Carers NSW is implementing both of these approaches as part of a Strategy project on identifying carers in social housing. At the time of writing, six community events in areas with high concentrations of social housing had already been attended by Carers NSW staff in order to reach hidden carers in priority population groups. Carers NSW staff have reported contact with over 700 people through these events, and conversations with at least 400, many of whom had not previously identified as carers. An online training module is also under development to help FACS social housing staff to identify and support hidden carers.

Carers NSW believes this project will result in many hidden carers being identified and accessing support, and that similar approaches could be taken to reach hidden carers in other parts of the community.

Carers NSW experience delivering the Young Carer program and working with the NSW Government on Young Carer projects from the Strategy, including the young carer app, the #ycproject video and young carer mentoring, has indicated that there is a particular need to reach hidden young carers. Young carers in regional areas are particularly likely to be hidden, and are difficult to reach through the existing Sydney-based Young Carer program.

Educators, like other mainstream service providers, can be key partners with the NSW Government in

***'I think that if someone had picked up in high school that I was a young carer and helped me to receive services earlier, I think it would have made a real difference to me maybe finding things to help me go to university while looking after mum and also to help me when I was doing my HSC.'***

**Young carer**

identifying and supporting hidden carers. The vast majority of children and young people attend educational institutions on a regular basis, and many experience problems participating in education as a result of their caring responsibilities.

Training staff of educational institutions to understand the impact of caring on children and young people, and how to identify and support hidden young carers, is therefore a critical opportunity in reaching hidden carers in NSW. One way this could be achieved is through the appointment of Young Carer Champions, nominated teachers or other staff members who are responsible for raising awareness of young carers among staff and students and implementing strategies to support young carers.

### 1.3 Expanded peer support network for carers

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

4. Continue to fund the expansion of carer peer support groups in NSW.

The importance of peer support for carers is acknowledged in Focus Area 2 of the Strategy. Carer support groups are a key source of peer support for carers in NSW, and can provide emotional support, reduce isolation, facilitate access to social services and enable carers to learn from the experiences of people in similar caring situations.<sup>6</sup>

Carers NSW has experience in the coordination of carer support groups through the delivery of *together* program, which connects and resources support groups for carers of people with disability. Carers NSW has seen first-hand how the NSW Government's investment in this program has strengthened the support available to carers across NSW, and allowed carer peer facilitators to learn from each, share resources, and increase their skills.

Carers NSW notes that demand to join the program is high, and regrets that we have to turn away carer support groups which are targeted at carers of people with dementia and other conditions. Member organisations of our Strategic Carers Action Network (SCAN) have also noted that demand for carer peer support from carers of people with dementia is a growing, unmet need. Increased resources and funding would enable more carers in NSW to benefit from effective, sustainable models of peer carer support.

Diversity and innovation in carer peer support groups should be encouraged wherever possible by flexible programs and funding models, including one-off grants. Carers should also be resourced wherever possible to start, sustainably maintain and expand peer-led groups where they see opportunities to reach out to other carers in their network or community.

The Carers Craft Studio in Coffs Harbour is a great example of how seed funding can enable innovation in carer peer support that meets a local need, establishes best practice and inspires

carers across NSW. The Carers Craft Studio was founded by a Carers NSW staff member in 2013. It is a weekly craft meeting intended to provide a positive respite experience for carers, drawing on the mental health benefits of craft that she had personally experienced as a carer.<sup>7</sup>

#### **Case Study**

Annaliese\* and her partner Richard\* have two sons with autism spectrum disorder. Annaliese discovered the Carers Craft Studio when the family moved to Coffs Harbour. The Carer Craft Studio helped Annaliese recognise her caring role, access carer support services and get to know other carers in her local area. The new support made her feel much less isolated, depressed and stressed, and gave her a regular break to look forward to. Annaliese believes that being a part of the Carers Craft Studio has helped improved her mental health, increased her confidence and improved her coping skills as a carer, which has also positively impacted her family life. Annaliese now hopes to become a facilitator of her own Carers Craft Studio.

\* Names changed

#### **1.4 Aboriginal Carer Network**

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

5. Establish an *Aboriginal Carer Network* to connect and better resource Aboriginal carers, organisations and community groups across NSW.

Carers NSW is one of a number of stakeholders partnering with the NSW Government to deliver Commitment 3.4 within the Strategy - *Information for carers in Aboriginal communities*. This initiative is focused on developing and distributing practical resources for Aboriginal carers, and has already made progress with the development of an updated *Taking Care of Business: Planning Ahead for Aboriginal people in NSW* resource.

However, the group's ability to distribute this tool, and capacity to develop and distribute further resources, is currently limited because there is not an established structure or mechanism which facilitates engagement and consultation with Aboriginal carers. We therefore propose that the NSW Government invest in the establishment of an Aboriginal Carer Network to enhance the delivery of information, resources and support to Aboriginal carers.

An Aboriginal Carer Network would invite carers and professionals working with carers in Aboriginal communities to be linked together in order to share information, events, carer stories, opportunities, tools and resources. The Network would support the work that the NSW Government and partners are undertaking through the Strategy, and would facilitate regular,

ongoing communication on Strategy projects from a wider range of stakeholders and carers. However it would also have a broader capacity to offer ongoing, online information sharing and promote visibility and awareness of Aboriginal and Torres Strait Islander carers.

Key components of the Network could include a dedicated webpage, a regular online bulletin, and a social media page which would allow members to engage with each other directly. These resources would be user-friendly, culturally appropriate and highly relevant to Aboriginal and Torres Strait Islander communities. A broad range of stakeholders from metro, regional, rural and remote areas would be targeted to join the Network, and would be invited to contribute to Network publications.

Although the Network could not replace face-to-face engagement with Aboriginal and Torres Strait Islander communities, it represents a practical and cost-effective opportunity to communicate about carer issues to a broader audience, and would be particularly useful for carers and workers living in rural and regional areas, who in our experience are more likely to be isolated and unaware of available supports and services. The Network would also provide a platform for local communities to share their stories and successes with a broader audience, and progress the NSW Government's broader goals of reconciliation between Aboriginal and Torres Strait Islander peoples and other Australians.

## 2. Carer inclusive mental health services

Carers NSW welcomed the NSW Government's investment in mental health in the 2015-16 State Budget, and endorsement of the NSW Mental Health Commission's *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024* (the Strategic Plan). In previous submissions Carers NSW has advocated for an expanded focus on community-based care, and we commend the NSW Government for striving to actively improve access to clinical services in the community and expand psychosocial community living supports.<sup>8</sup>

The Strategic Plan identifies the vital roles that families and carers play, and notes that an effective system of mental health care values carers' contribution to the recovery of consumers, and care for the carers themselves.<sup>9</sup> Our recommendations for mental health services are aligned with the goals of the Strategy and focus on practical, achievable actions that will benefit diverse carers of people with a mental illness in NSW.

### 2.1 Review of the *Mental Health Act 2007*

#### **Carers NSW recommends that NSW Health:**

6. Ensure that adequate resources are available to inform and educate carers about the changes to the *Mental Health Act 2007* and their rights under the Act.

In 2012 NSW Health's Mental Health Drug and Alcohol Office (MHDAO) began an extensive review of the *Mental Health Act 2007*. Throughout this process NSW Health demonstrated that they were responsive to feedback around the strengths and gaps in the legislation, and Carers NSW commends NSW Health for its broad-based consultation process. Carers NSW welcomes the outcome of the review, which has seen strengthened provisions for carers enshrined in the Act through the *Mental Health Amendment (Statutory Review) Act 2014*.

During the review process Carers NSW noted that carers' experiences revealed that the Act had been interpreted narrowly and implemented inconsistently. Many carers were unaware of their rights under the Act, and a survey conducted by Mental Health Carers ARAFMI NSW (ARAFMI NSW) found that a large percentage of people who were acting as primary carers were not informed about the laws that gave them these rights as carers.<sup>10</sup> ARAFMI's member survey also found that when carers had an awareness of their rights under the Act, this knowledge had been gained predominantly from non-government sources rather than public mental health services.<sup>11</sup>

Carers NSW anticipates that the revised Act will have positive outcomes for carers, who often feel excluded from mental health services, and we expect that the changes will see carers more consistently identified, considered, consulted, included and respected. In order for the legislation to have an impact on the ground, it is critical that the Review of the Act is followed up with information to health professionals, consumers and carers about the changes, so that the amended legislation is understood and practiced consistently across NSW. Whilst changes to the Act have passed, it appears that education, training and resources to accompany these changes have lagged behind. A comprehensive education program and updated resources which specifically target carers should be funded by NSW Health.

## 2.2 Carer peer workers

### **Carers NSW recommends that NSW Health:**

7. Invest in a pilot carer peer worker study to build the evidence base on carer peer workers in mental health services in NSW.

As part of its plan to strengthen mental health care in NSW, the NSW Government has committed to strengthening the mental health workforce. NSW Health have particularly emphasised their commitment to support the development of the peer workforce,<sup>12</sup> and Carers NSW is keen to ensure that due attention is given to the expanding of the carer peer workforce.

The NSW Mental Health Commission have noted that the peer workforce in NSW is 'small, under-supported and under-resourced', and Carers NSW notes that the carer peer workforce is particularly underdeveloped. It is difficult to scope the number of carer peer workers in NSW

due to role variation and a lack of systemic evaluation, however the most recent evidence we have suggests that the limited number of carer peer workers are mainly employed in community managed organisations, and that they are largely absent from public mental health services.<sup>13</sup>

The evidence we have to-date highlights the enormous potential of carer peer workers to support the caring role, promote carers' wellbeing and advance the family and carer specific goals of the Strategic Plan. For example, one Action within the Strategic Plan is to:

**4.1.4** Ensure that in assessing a person's family and carer circumstances, advice is always provided about where to find more information and support for family members and carers, and that where required, assistance is provided in accessing these. This will include access to respite care, Centrelink benefits and return-to-work programs for carers, and information and advice on family and carer support groups.

This Action also reflects the principles of the *NSW Carers Charter*, which encourages health services to find out what supports and services carers need and refer them to those services.<sup>14</sup> Peer workers who have navigated the system are well placed to advise family members and carers on how they can access appropriate and timely support, and provide referrals to local services.

Health Workforce Australia's extensive *Mental Health Peer Workforce Study* noted that much like consumer peer workers, carer peer workers' capacity to connect with someone who has had similar experience is a critical factor in their effectiveness.<sup>15</sup> Carer peer workers can provide much needed emotional support to carers, who are likely to be experiencing reduced mental wellbeing as a result of their caring role.<sup>16</sup>

The study also highlights carer peer workers' important role in providing family education and their capacity to ease the burden on families:

*'In a very practical way...By sharing the load, they can empower families and staff to communicate more sensitively and to work more collaboratively.'*<sup>17</sup>

ARAFMI NSW, who have extensive experience employing carer peer workers within their organisation, argue that peer workers 'would humanise the face of mental health treatment'<sup>18</sup> and that carer peer workers can support carers to:

*'become proficient in delivering the right degree of support to their loved ones, and allow them to reclaim their own lives.'*<sup>19</sup>

Literature on peer work also highlights the benefits of peer workers in providing culturally appropriate care to diverse groups, including Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds.<sup>20</sup>

In addition to providing direct support to families and carers, peer workers also typically play a key role in shaping the culture of mental health services,<sup>21</sup> and carer peer workers could promote family and carer inclusiveness in service delivery.

Carer peer workers represent a huge untapped asset to our mental health services, and Carers NSW encourages the NSW Government to take the first steps needed to establish carer peer workers in public mental health services. Considering the limited evidence to date about the carer peer workforce, Carers NSW recommends that a good first step would be to invest in a small-scale pilot program of carer peer support workers. Considering that role clarity is a common challenge experienced by peer workers,<sup>22</sup> a pilot study would provide an opportunity to explore the most effective roles for carer peer workers, and consider how these roles can be integrated into the current service landscape.

### 3. Carers focussed health system

The sustainability of the NSW health care system depends on the contribution of unpaid carers, who are the major providers of health care in the community.<sup>23</sup> Across NSW, Carer Support Programs are doing important work within their Local Health Districts (LHDs) to create health systems which are more responsive to the needs of carers. Several of our recommendations call for greater investment in work that originated through the NSW Health Carer Program, and could improve the experiences of carers across NSW.

Carers NSW is pleased to see that the NSW Government is delivering on its commitment to advance integrated care in our health services, an investment which the Ministry of Health has stated will *'benefit carers and families as well as users of the health system'*.<sup>24</sup> Carers NSW is a keen advocate for better integrated health services, and this submission also calls for health services to work in partnership with aged care and disability services during this period of widespread sector reform, to ensure that patients and carers do not fall through the gaps.

#### 3.1 Investing in the TOP 5 Initiative

**Carers NSW recommends that NSW Health:**

8. Provide ongoing, sustainable funding to progressively roll out the TOP 5 initiative across NSW.

The TOP 5 model was first developed in the Central Coast Local Health District, who describe TOP 5 as a 'win-win-win for the person, carer and staff.'<sup>25</sup> The TOP 5 model encourages staff to communicate with carers and draw on their expertise in caring for patients with cognitive impairment. From these discussions, five strategies are identified and written onto the TOP 5 form, which is available to all staff involved in the patient's care, and is used to support the patient in their hospital admission and beyond.

The TOP 5 model is now being implemented in selected hospitals across the state, and is being evaluated by the Clinical Excellence Commission (CEC) who are focusing on the usefulness of the model in transitions of care between local residential and aged care facilities, community services and ambulance services. The first phase of the CEC's evaluation of the program in acute care settings has already revealed that implementation of the TOP 5 can really be a win-win-win, with significant benefits for patients, carers and clinicians. The CEC's report, *TOP 5: Improving the Care of Patients with Dementia 2012-2013*, revealed that the TOP 5 model promoted safer, better quality health care, and resulted in reduced falls, reduced use of anti-psychotics and reduced need 1:1 intensive nursing care.<sup>26</sup>

The report found that carers themselves were very positive about the program, conveying high levels of satisfaction with the way staff had used the TOP 5 strategies (97 per cent). A significant majority of carers agreed that TOP 5 had benefitted the patient (85 per cent) and identified that the patient was calmer as a result of TOP 5 (82 per cent).<sup>27</sup> Carers with experience of a previous patient hospitalisation reported higher levels of satisfaction with staff relations when TOP 5 was in place, compared to previous admissions without TOP 5.

Carers NSW believes that the TOP 5 initiative reflects current best practice for working with carers. The TOP 5 program upholds principles of person centred care and reflects the principles enshrined in the *NSW Carers Charter*, encouraging health staff to listen to carers, respect carers' knowledge and experience and to respect the relationship between carers and those they care for. We anticipate that TOP 5 will be successful for a broader range of patients with a cognitive impairment across a range of care settings, and therefore urge NSW Health to get behind this initiative, and provide ongoing funding for it to be rolled out across NSW.

### 3.2 On-site accommodation for carers

**Carers NSW recommends that NSW Health:**

9. Invest in appropriate on-site accommodation designed for carers supporting patients in hospital.

Family members and carers provide critical support to their loved ones during a hospital stay. Carers can provide reassurance and support to the patient, facilitate communication with health professionals, support the delivery of optimal, person-centred health care, act as an

advocate, monitor health care treatment and compliance, and may assist with practical tasks such as feeding and showering. Carers' contribution to the care of the patient often has a direct benefit to hospital staff, but most hospitals are not designed with their presence in mind.

In an attempt to gauge the need for carer-friendly spaces, one Local Health District conducted a survey with Nurse Unit Managers across ten of its wards in a major metropolitan hospital. The survey found that between 2014 and 2015, an estimated 477 patients had a family member or carer stay overnight, with a total of 3070 overnight stays<sup>28</sup>. Whilst some accompanied patients in single rooms, family members and carers often slept in chairs next to patients in shared rooms.<sup>29</sup> The estimated average length of stay was four days, with the longest stay being over 30 days.

This LHD found that having a family member or carer stay overnight benefits the patient, family member or carer and staff. They reported that:

*'The benefit of decreased falls, anxiety, reduction in self-harm and patients removing their cannula when delirious would reduce number of admission days and offer better health outcomes for the patient as well as considerable financial savings.'*

The evidence collected by this LHD reflects the experiences that carers report to Carers NSW when they are supporting their loved one in hospital. This time is usually a period of crisis for carers, and this difficult time is only compounded when carers sacrifice their sleep and comfort to support their family member, partner or friend.

Carers NSW welcomes the NSW Government's ongoing investment in building and upgrading hospital facilities, and suggests that it is essential that our hospitals include carer-friendly spaces, including specifically designed rooms and beds for families and carers to visit and stay overnight.

### **3.3 Carers' needs in Connecting Care Chronic Disease Program**

**Carers NSW recommends that NSW Health:**

10. Increase funding to the *NSW Chronic Disease Management Program* to improve support for carers.

Carers NSW welcomes the efforts of the NSW Government, through the NSW Carers Strategy, to address the health needs of carers by building on and expanding existing health screening and intervention programs, such as community based health check programs, that are easily accessible and promoted to carers. The Strategy recognises that carers need health services

that are flexible and health professionals who ask about their wellbeing and make it easy for carers to get their own health needs met at the same time as those they care for.

Carers NSW believes that the NSW *Chronic Disease Management Program- Connecting Care Chronic Disease Program* (CDMP) is one program which is well placed to better target and engage with carers to promote better health outcomes. The CDMP provides care coordination and self-management support to help people with chronic disease manage their condition and access appropriate services, in order to improve health outcomes and reduce their need for hospitalisation. A key aim of the CDMP is to work with family and carers, who alongside with the patient themselves, are responsible the vast majority of care.<sup>30</sup>

A recent report produced by South East Sydney Local Health District (SESLHD) has highlighted the potential for CDMP to routinely identify and provide ongoing support to carers of people who are engaged in the program. *Carers Needs in the Chronic Disease Setting: Pilot Project Report* reports on the findings of a survey of 50 carers of people looking after someone with a chronic disease who were recruited through the CDMP. Carers reported a number of positive aspects of the program, including that it provided them with a wide range of information and was personable, reassuring and caring. However the report identified that many carers were confused or unaware of health professionals' specific roles and had little of knowledge of support services, and almost half said they didn't have time to look after their own health.<sup>31</sup>

The report also identified that many carers experienced the same health risks as the person they care for, and were likely to share their lifestyle risks. These findings should be considered in light of research which highlights carers' elevated risk of chronic disease. One Australian study found that carers are 40 per cent more likely to suffer from at least one chronic health condition when compared to the rest of the community, and are more likely to report risk factors including high blood pressure and high cholesterol. Carers were also more likely to be categorised as overweight or obese, and be experiencing chronic pain or carrying an injury associated with caring.<sup>32</sup>

The SESLHD report clearly demonstrates that carers have a significant need for support, information and advice, and that staff working in the CDMP can play an integral role by routinely identifying, assessing and supporting carers. The report adds to a significant body evidence which highlights that we need to be doing a lot more to keep carers healthy. Increasing funding to the CDMP so that it can actively focus on carers would be a step in the right direction.

### 3.4 Aids and equipment for over 65s

#### **Carers NSW recommends that NSW Health:**

11. Work with the Commonwealth to ensure that there are no funding gaps for people on Commonwealth Home Care Packages who require aids and equipment.

Carers NSW acknowledges the vital support that Enable NSW provides to people with chronic health conditions or disability in NSW, and was pleased to see its funding increased in last year's State Budget. However, we are concerned that NSW residents over the age of 65 who need aids and equipment may be disadvantaged by cost-shifting between the NSW and Commonwealth governments.

To our knowledge, people who are recipients of a Commonwealth Home Care Package (HCP) are no longer eligible to receive aids and equipment, including continence aids, through Enable NSW.<sup>33</sup> However, while Commonwealth HCPs may fund some aids and equipment, funding is capped and may be insufficient to meet all a person's aids and equipment needs. The Commonwealth expects additional costs associated with aids and equipment to be covered by the individual or by state-based aids and equipment programmes, as needed.<sup>34</sup>

Concerned carers and stakeholders have reported to Carers NSW that the ineligibility of people on HCPs for Enable NSW is leaving some people without needed aids and equipment. Carers NSW is concerned that people on HCPs, especially lower level HCPs with minimal funding attached, may rely on their carer to fund these items, which may not be affordable for them, or to risk their own health and wellbeing trying to compensate for the shortfall.

#### **Case Study**

Ben\* is over 65 and was on the waiting list for 18 months for a wheelchair through Enable NSW. During that period, he became eligible for a HCP. When a wheelchair became available through Enable NSW he was denied it because of his HCP, however his HCP plan did not include funding for a wheelchair. As a result, he was unable to access this necessary equipment.

\* Names changed

### Case Study

Bernard\* cares for his elderly mother Joy\* who has a disability. Before becoming eligible for a HCP, Joy received continence aids through Enable NSW and was assessed as requiring a wheelchair. Once she got her HCP, she was no longer eligible for continence aids from Enable NSW, and her application for a wheelchair was rejected. However, her HCP budget was insufficient to meet the costs for either of these items. As a result, Joy had no choice but to pay \$2,500 per year from her Age Pension for continence pads. She does not know how she will afford a wheelchair. The stress caused by the situation has adversely affected Bernard and Joy's relationship and severely impacted their mental health and wellbeing.

\* Names changed

In late 2014, it was reported that the NSW and Commonwealth Governments were exploring the budget implications for Enable NSW continuing to fund aids and equipment for people with HCPs, and that any changes would require significant additional funding.<sup>35</sup> Carers NSW believes that the NSW government needs to continue to work with the Commonwealth to ensure that older people and their carers receive adequate aids and equipment whilst being a Home Care package consumer.

### 3.5 Disability and health

#### **Carers NSW recommends that NSW Health:**

12. Establish clear funding arrangements between NSW Health and disability services which will promote appropriate, timely care for people with disability and carers.

The intersection between health and disability services will come into sharp relief next year as dramatic sector reform continues, and it is essential that systems work together so that people with disability and the carers who support their health receive timely and appropriate health care.

It is widely acknowledged that people with disability and their carers experience poorer health outcomes than the rest of the community, and that their experiences in accessing health services in NSW do not meet community standards.<sup>36</sup> People with disability face multiple barriers in accessing health services. These barriers, including inaccessible health environments and attitudinal barriers, profoundly impact carers, who play a key role in supporting the health of people with disability in the community, and navigate health services alongside them.

Carers are often relied upon by under-resourced, over-stretched health services to meet the basic support needs of people with disability during their health treatment. However, carers'

understanding of the people they care for, knowledge of the history of their health care, and expertise in managing their health can be sidelined and devalued by health systems which do not recognise or value carers' critical role. Properly resourcing health services to provide optimal service to people with disability is therefore a critical issue for carers in NSW.

Disability organisations have highlighted key challenges which the roll out of the National Disability Insurance Scheme (NDIS) presents to the health system in NSW. These must be considered and addressed by Ageing Disability & Home Care and NSW Health as they negotiate the transition. The National Disability Services 2014 paper *People with disability and hospitalisation: Challenges and opportunities in NSW* is a particularly useful overview of the key issues and provides clear direction for how the health care of people with disability and their family and carers can be improved through this transition. One of its central recommendations is the development of:

*'A state-wide agreement defining a minimum standard of support provision which:*

- *Resources support provision.*
- *Sets minimum standards of knowledge and care expected of hospital staff.*
- *Clarifies how the roles of health and disability support staff can be decided upon in a person centred manner.*<sup>37</sup>

Carers NSW welcomes actions taken by NSW Health to date which reflect this recommendation, including the pending publication and implementation high level policies and frameworks such as the *Disability Inclusion Action Plan (DIAP)* and the updated Policy Directive, *People with a Disability: Responding to Needs during Hospitalisation*. Carers NSW is pleased to see that early drafting of the DIAP indicates that it recognises carers' right to be included and involved in service design and delivery as partners in care.<sup>38</sup> However, there remains a need for clarity around funding arrangements and who is responsible for resourcing support for people with disability and their partners in care.

### **3.6 Carers' experiences of health services**

#### **Carers NSW recommends that NSW Health:**

13. Measure and report on outcomes for carers who are accessing NSW Health services.

In this year's submission Carers NSW again emphasises the importance of routinely collecting information from carers themselves in order to track how well we are identifying, recognising, including and supporting carers in health services.

Whilst state-wide instruments (including the Patient Survey program and *Your Experience of Service* questionnaire) gauge patients' and consumers' experiences of health and mental health services, the identification and measurement of carers' experience of service is

inconsistent within Local Health Districts, and often entirely absent. Feedback from carers must be embedded in ongoing evaluation of NSW Health services, and be used to shape important reforms, including Integrated Care.

## 4. Transition to the NDIS

July 2016 will mark the third anniversary of the National Disability Insurance Scheme (NDIS) in NSW and the beginning of the full rollout. From 1 July, people not reached by the NSW trial and early rollout will begin to transition in seven districts across NSW, with a further nine districts coming on board from 1 July 2017. In 2016-17 alone, it is expected that over 40,000 people will be brought into the NDIS.<sup>39</sup>

The first two years of the NDIS have seen major changes in parts of the NSW disability sector and positive outcomes and achievements for many people with disability and their families and carers. There have also been a number of key challenges, especially for carers.<sup>40</sup> Since our 2015-16 pre-budget submission, information and capacity building for people with disability and their carers have considerably improved. There is much greater clarity around when and how the NDIS will roll out in NSW and what will exist outside individual packages.

However, the National Disability Insurance Agency (NDIA) and NSW Government still have a long way to go in ensuring that no carer is worse off with the transition to the NDIS. This section makes some practical recommendations about how the 2016-17 Budget can contribute to this important objective.

### 4.1 Maintaining support for carers

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

14. Work with the Commonwealth to ensure that there are no service gaps for people with disability and their carers in the lead up to the NDIS and after full rollout.

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

15. Ensure that there remains a provider of last resort for people with complex needs.

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

16. Continue to provide and improve information, communication and capacity building opportunities for carers about the NDIS in NSW.

In the second half of 2015 Carers NSW welcomed the release of the Information, Linkages and Capacity Building (ILC) policy<sup>41</sup> and the publication of the bilateral agreement between the Commonwealth and NSW Governments on the rollout of the NDIS<sup>42</sup>. Carers NSW has also been

pleased to hear of the Commonwealth Government's plans to establish a National Carer Gateway and Integrated Plan for Carer Support Services, which will provide support to carers separate to and alongside the NDIS.<sup>43</sup>

However, with ADHC services fully transitioning to the NDIS by full rollout, Carers NSW remains concerned that some people with disability and their carers will be worse off in the transition to the NDIS.<sup>44</sup> It is still unclear what the scope of ILC supports will be, and whether there will be sufficient funding to meet the support needs of all people with disability and carers, including those who will be ineligible for NDIS packages, or who are currently receiving supports that will not be replicated in NDIS packages.<sup>45</sup>

The NDIS is expected to support 140,000 people in NSW from 2018.<sup>46</sup> However, there are over 400,000 people under 65 with a reported disability in NSW who need assistance with at least one activity<sup>47</sup>, not to mention the thousands of other NSW residents with a mental illness in need of support. In the quarter ending 30 June 2015, the ineligibility rate for people requesting access to the NDIS in the NSW trial site was 11 per cent<sup>48</sup>, the highest of any state. If this continues, more than one in ten people wishing to access the NDIS risk being left without adequate support.

Further, the NSW Government currently funds a number of programs that provide supports and services directly to carers, including information, advocacy, respite, support coordination and peer support groups. One key example is the Older Parent Carer Support Coordination Program, which provides valuable individualised support to carers of adults with disability. The devolution of ADHC assumes that the NDIS will simply take over ADHC's role in providing all disability services. However, there is no guarantee that equivalent carer specific supports and services to those currently funded by ADHC will be covered under the NDIS.<sup>49</sup>

Carers NSW has heard from carers and service providers that high demand for supported accommodation continues, especially among families containing ageing parent carers. Many families cannot wait until the NDIS for supported accommodation as their caring situation is currently unsustainable due to health or other factors. However, some have been receiving messages that no additional supported accommodation will be provided in the lead up to the NDIS. FACS must clarify with families how continuity of support will be achieved in the lead up to, and after, the rollout of the NDIS.

Carers NSW believes that the NSW Government has a responsibility to ensure that there remains a provider of last resort in NSW. The NSW Government is currently the provider of last resort for people with disability or a mental illness. The transition to the NDIS is intended to give people more choice and control, but may unintentionally disadvantage people with complex support needs, who may be refused service by non-government providers if their support costs are high. If people with complex support needs are refused service, their carers

may have no other option than to take on a more intensive caring role, placing their own wellbeing at risk.

Finally, carers need ongoing, up to date and accessible information on the NDIS as it rolls out in NSW. The recently launched NSW NDIS website and accompanying fact sheets and resources are a significant improvement on the previously limited and wordy sources of information on the NDIS website. The introduction of Community Connectors in the Nepean Blue Mountains site has also been a valuable innovation, providing families with considerably more support than the families that transition as part of the Hunter trial.

However, carers still report that they are confused, overwhelmed and anxious about the changes, and that it is difficult to find accurate, current and easy-to-read information amid the mass of information available. The NSW Government must continue to consult with carers and stakeholders to ensure that information is reaching carers and meeting their needs. It must also ensure that information is up to date and accessible for diverse carers.

#### **Case Study**

Amanda\* lives in the Nepean early rollout site for the NDIS and has begun the process of requesting access to the NDIS for her young child. She has been very confused and distressed by the process and, despite doing her best to find information and support, continued to reach dead ends until she contacted Carers NSW. Despite being connected with local disability services, she was not aware of the Community Connectors in her local area.

\* Names changed

#### **Case Study**

Raeleen\*'s daughter Jodie\* is in her forties and has an intellectual disability. Raeleen is scared and confused about the NDIS. She struggles to keep on top of all the written information that is available, and feels much of it is still very vague. She has attended a lot of meetings where service providers try to explain the NDIS, but that she and others have only come out more confused. She gets the sense that even they don't understand what is happening.

\* Names changed

## 4.2 Carer awareness

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

17. Prioritise carer awareness training for service providers in the allocation of funding for the Disability Sector Transition Fund.

Carers NSW acknowledges the sale of Home Care NSW to experienced care provider Australian Unity, and is pleased that Home Care will transfer as a single entity, with its valuable Aboriginal Home Care component being retained. We welcome the announcement that the \$100 million revenue from the sale will be reinvested to establish a Disability Sector Transition Fund to support the rollout of the NDIS in NSW.<sup>50</sup>

Carers NSW believes the establishment of this fund is a timely and valuable opportunity to maintain and improve the carer awareness of the disability sector as it transitions to the NDIS. The NSW Government has developed a strong record of recognising, including and supporting carers. There is a risk that as it withdraws from direct service provision to people with disability and their carers these assets will be lost, as carer inclusion and support within the NDIS is limited,<sup>51</sup> and many NDIS planners do not have specialist skills or knowledge relating to disability and carers.

Now more than ever, disability service providers require the skills and resources to balance the needs and goals of people with disability and their carers and achieve positive outcomes for both within the new system. Training in carer awareness, identifying hidden carers and dealing with family disagreement and conflict will be valuable to service providers promoting their services to families, and even more valuable to families accessing services with NDIS participants.

## 4.3 Evidence of disability

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

18. Expand funding within existing services and programs, to enable more families to obtain evidence of type, level and impact of disability to assist them with applying for the NDIS.

To find out whether a person with disability is eligible for the NDIS, the person or their carer will need to provide evidence of their disability, including diagnosis, whether the disability is likely to be permanent, how the disability impacts their daily life, and any treatments they are receiving. Families can have a treating doctor or specialist complete this information in the

NDIS Access Request form, or they can simply provide copies of existing assessments and reports from specialists or health/allied health professionals.<sup>52</sup>

The NDIS works with families making an Access Request to identify what evidence is required and advise if they need to obtain further diagnosis or assessment information. However, the NDIA does not have the capacity to provide in-depth referral or coordination before someone is determined as eligible for a plan. There is also no funding available within the NDIA to help those families who do not yet have a plan to access or meet the costs of diagnosis and assessment.<sup>53</sup>

Some families will already have all the evidence required to access the NDIS, or at least the capacity and financial means to obtain it. However, some families may require practical and financial support to obtain appropriate evidence. Many families will be able to access such support through ADHC funded programs and the public health system, including through funded diagnostic services.

#### **Case Study**

Clients of the ADHC funded Older Parent Carer Support Coordination Program (delivered by Carers NSW in South East Sydney, Mid North Coast and Orana Far West) benefit from support coordination and an individual package of funds to assist with future planning. Support coordinators are able to assist older parent carers to find out what diagnosis and assessment reports are necessary for eligibility for various disability supports, including the NDIS, and direct them to the appropriate places. They are also able to use some of their funding to meet the costs of diagnosis and assessment if they wish.

However, Carers NSW is concerned that not all families will be able to access local and affordable diagnosis and assessment, prohibiting their ability to demonstrate eligibility for the NDIS. We are also concerned that as the full rollout begins in July 2016, the NDIA and public health services in new rollout districts will experience high demand, which may lead to delays in families accessing NDIS support.

Families who do not have the means to obtain diagnosis and assessments privately, or to travel to appropriate services from rural and remote locations, may therefore be disadvantaged. This has been the case for some families hoping to access the Commonwealth funded Better Start for Children with Disability initiative, for which Carers NSW undertakes registrations.

### Case Study

Carers NSW staff registering parents of young children with disability for Better Start have known of families who have struggled to afford the specialist appointments and tests required to obtain a diagnosis to qualify for the program. In some cases these costs have prevented families from accessing Better Start funding, meaning that their children missed out on critical early intervention support. Staff have expressed their concern that the cost of obtaining a diagnosis to confirm eligibility may also deter some families from accessing the NDIS.

Carers NSW commends the NSW Government on existing and new practical and financial support for families seeking diagnosis and assessment, especially those particularly addressing NDIS transition. However, Carers NSW believes that FACS and NSW Health could do more to ensure that families both within and outside the existing disability service system are aware of the need to obtain evidence of disability and have the capacity and means to do so in a timely manner.

#### 4.4 Direct employment

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

19. Commission a review to identify how legislation, policy and systems in NSW can be improved to facilitate direct employment.

Carers NSW commends FACS for investing growth funding in the disability sector through *Ready Together* and the *Living Life My Way Framework* to enable people with disability and their carers to get used to individualised and self-managed supports. Offering Direct Payment Agreements (DPAs) to recipients of certain individualised FACS programs is a great way of preparing people with disability and their carers for the NDIS and improving their quality of life while they wait for it to arrive their area.

The FACS DPA Handbook is a comprehensive and easy-to-read guide assisting people to understand and implement their DPA.<sup>54</sup> However, it is clear from reading this guide that no matter how simply it is explained, managing a DPA is complex and not for everyone. Employing one's own staff can be especially complex and require a high level of skill, understanding and involvement.

Carers NSW is concerned that some people with disability and their carers may unwittingly place themselves at risk due to taking on more work than they anticipated, or incurring legal or financial liabilities they are unaware of. FACS has an arrangement with legal firm Ashurst to provide free legal advice to people interested in signing a DPA.<sup>55</sup> However, ongoing expert

legal and financial advice must be made available to people with disability and carers who choose to manage their support in this way.

Furthermore, it was apparent from a recent Ashurst seminar on direct employment attended by Carers NSW, that confusion still exists among people with disability and their carers, and even among legal professionals and FACS staff, about some of the legal and financial implications of direct employment. Existing legislation and information systems relating to highly important matters such as taxation, insurance and unfair dismissal still contain grey areas for people directly employing workers with individualised funding.

Given that direct employment is gaining popularity in NSW and will remain a part of the NDIS into the future, Carers NSW believes that all relevant legislation, policy and systems in NSW should be reviewed and amended as necessary to ensure that people with disability and their carers are protected and that accurate and consistent information is available. This will ensure a robust framework that promotes direct employment as a viable option for more people with disability and their carers.

## 5. Carer rights

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

20. Undertake the review of the *NSW Carers (Recognition) Act 2010*.

In 2010 the NSW Government demonstrated its commitment to supporting carers through the enactment of the *NSW Carers (Recognition) Act 2010* (the Act), which established the NSW Carers Advisory Council and formally recognised the significant economic and social contribution that carers make to the community in NSW.

Carers NSW strongly supports the intention of the legislation and the proposed direct benefits for carers flowing from the implementation of the Act and the Carers Charter, such as increased opportunity for workforce participation; improved health and quality of life through meaningful employment; increased financial security; increased opportunity for social inclusion; the ability to provide input to public service policy and program development on matters that affect carers; and referral to appropriate support services and enhanced support for the person they are caring for.

As noted in last year's pre-budget submission, it is now time to review the *Carers (Recognition) Act 2010* in line with the legislative requirement to undertake a review as soon as possible after the period of 5 years from the date of assenting. This process will provide an opportunity to reflect on how the intention of the legislation is being fulfilled, and how it can be

strengthened to improve the lives of carers and the practices of public sector and human service agencies in NSW.

## **Conclusion**

Carers NSW would like to thank the NSW Government for its ongoing commitment to carers and the opportunity to contribute to the future direction of our state. This submission has drawn attention to five key areas in which we can make it happen for carers, and we urge the NSW Government to consider our recommendations as it prepares the 2016-17 Budget.

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

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