

# Supporting carers: achieving the vision

**Carers NSW 2015-16 pre-budget submission**

## **About Carers NSW**

Carers NSW has an exclusive focus on supporting and advocating for carers of all ages and circumstances in NSW. Carers NSW is the only state-wide organisation that has carers as its primary focus and is a member of the national Network of Carers' Associations.

Our vision is that all carers in NSW are recognised, valued and supported by the community and by governments. Our goal is for carers in NSW to have improved opportunities, choice and access to support that meets their needs and circumstances across their life span.

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

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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 850,000 carers, and to replace them the NSW Government would have to spend around \$15 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, with implications in terms of their participation in employment, education and community activities.

## **Carers NSW**

Roden Cutler House  
Level 18, 24 Campbell Street, Sydney NSW 2000  
Tel: 02 9280 4744  
Fax: 02 9280 4755  
Email: [contact@carersnsw.org.au](mailto:contact@carersnsw.org.au)  
Web: [www.carersnsw.org.au](http://www.carersnsw.org.au)

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## Introduction

The past year has seen important progress for carers in NSW. The NSW Government has articulated a strong, strategic vision for carers in our communities through the *NSW Carers Strategy 2014-19* (the Strategy), a blueprint for widespread reform. Carers NSW congratulates the NSW Government on the release of the Strategy, which reflects the priorities of carers in our state and is an important step in the ongoing journey towards improved carer support. At the launch of the Strategy the Honourable John Ajaka MP stated that:

*“Improving support for carers should concern the entire community; we want them to be healthy and live well”*

The provision of support to carers continues to be mediated by the changes and transitions which are occurring across all sectors, particularly as the National Disability Insurance Scheme (NDIS) is rolled out. We have previously asserted that these changes have the potential to positively transform the caring role, however this potential is as yet unrealised for many carers. There remains confusion surrounding the services and support which will be available to carers in this transition period, and we call upon the NSW Government to work in close partnership with the Federal Government to guarantee continuity of support for carers and their loved ones.

Carers NSW has undertaken extensive consultation with carers in the past year, which has informed our recommendations in this submission. In particular we will refer to two key reports we released this year, the *Carers NSW 2014 Carer Survey- Main Report* and our issues paper *The NDIS one year in: Experiences of carers in the Hunter trial site*.

Our 2014 *Carer Survey- Main Report* reveals the key findings of our 2014 Carer Survey which was completed by approximately 1,700 carers across NSW, and has collected more detailed data than any previous Carer Survey. The survey findings include that carers consistently emphasise positive aspects of their caring role, however most believe that recognition and acknowledgment of carers by services and the wider community is low. Our NDIS issues paper summarises key issues arising for carers from the first year of the NSW trial of the NDIS. The paper draws on research, consultation and policy analysis and contributes to the ongoing refinement of NDIS design and implementation.

The NSW Government has articulated a clear vision for caring communities for NSW. This submission will make a number of recommendations which the NSW Government can take to achieve this vision and improve support to all carers across NSW. Carers NSW will advocate for the NSW Government to:

1. Commit to carers
2. Support carers transition to the NDIS
3. Give extra support to ageing parent carers
4. Improve outcomes for carers in our health system
5. Facilitate transport for carers

## Summary of Recommendations

Carers NSW recommends that the NSW Government:

1. Attach funding to support the *NSW Carers Strategy 2014 -2019* in order to maximise outcomes for carers.

2. Commence the review of the *NSW Carers (Recognition) Act 2010*.

3. Fund more targeted information, resources and training opportunities to prepare carers to engage with *Ready Together* and the NDIS.

4. Fund more individual support and advocacy for carers.

5. Fund the development and delivery of carer awareness training for service providers and staff to support inclusion of carers.

6. Implement formalised carer assessment as part of person centred planning and assessment processes used under *Ready Together*.

7. Ensure that service provision and quality are not disrupted by staffing changes related to the devolution of ADHC.

8. Plan ahead to ensure that money remains within FACS to address service gaps for people with disability and carers not covered by the NDIS.

9. Continue the Older Parent Carer Support Coordination (OPC) Program after the full roll out of the NDIS.

10. Expand the Older Parent Carer Support Coordination (OPC) Program to reach more 'hidden carers'.

11. Ensure that LHD Demonstrator Sites, and programs funded through the Integrated Care Planning and Innovation fund:

- Include carers as partners in care
- Report on outcomes for carers.

12. Fund the development of tailored training and ongoing support for carers to 'have their say' in the health system.

13. Take action to keep carers healthy, by:

- Ensuring existing preventative health programs are community based and easily accessible by carers
- Identifying opportunities for promoting and targeting preventative health initiatives to carers.

14. Increase investment in carer inclusive community-based mental health services.

15. Raise the subsidy cap for the Taxi Transport Subsidy Scheme to \$60 per trip.

16. Strengthen its commitment to improve transport for health across NSW (especially in rural and regional areas) by providing details about how it will fund, implement and evaluate this goal within the next 2 years.

17. Increase their funding share of Community Transport providers to meet the growing need for non-emergency transport to health services across NSW.

**Note:** Unless otherwise specified, all quotations appearing in boxes are from respondents to the Carers NSW 2014 Carer Survey. All case studies are based on real carer stories, originating from our policy work, however names have been changed to preserve anonymity.

# 1. Committing to carers

## 1.1 NSW Carers Strategy 2014-2019

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

1. Attach funding to support the *NSW Carers Strategy 2014 -2019* in order to maximise outcomes for carers.

Carers NSW strongly supports the NSW Government's commitment to improve the position of carers in NSW. Carers NSW welcomed the collaborative approach that was undertaken in the development of the *NSW Carers Strategy 2014-2019*.

Carers NSW applauds the NSW Government for its commitment to supporting carers through the release of the Strategy. The commitments in the Strategy were developed in collaboration with a large number of stakeholders including carers, NSW Government and non-government agencies. As a result the commitments reflect the supports and services that would make a real difference to the lives of carers in NSW.

As the Strategy is a five year plan many of the commitments will roll out slowly over the course of the next few years. It is important now that the current collaborative momentum is maintained to make sure that the commitments have the best chance of making a difference to carers' lives and raising awareness of carers across NSW.

Carers NSW asserts that while the collaborative approach has drawn on collective resources we need a real investment in the Strategy from the NSW Government to ensure that the initiatives which have been developed have the best chance of being effective.

This funding is particularly important to reach diverse groups of carers. There are still many carers across NSW, and individuals who are providing support to family or friends who do not identify as carers, who do not access services and support, particularly those from Aboriginal and Torres Strait Islander carers, and carers from culturally and linguistically diverse backgrounds. Carers NSW encourages the Government to fund the Strategy commitments in order to reach these carers and support their caring role in a respectful and culturally safe way.

## 1.2 Carers (Recognition) Act 2010

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

2. Commence the review of the *NSW Carers (Recognition) Act 2010*.

The NSW Government has shown that it is committed to supporting carers through the enactment in May 2010, 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.

The Act and the NSW Carers Charter placed clear obligations and responsibilities on public sector and human services agencies to recognise and value carers and ensure carers are consulted on policy matters that impact on them. It is now time to review the improvements that the Act has made to the lives of carers, and to the practices of public sector and human service agencies in NSW.

Carers NSW strongly supported 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.

It is important to know how and in what ways the the Act and the Carers Charter have made a difference to the lives and wellbeing of carers in NSW over the almost five year period since the Act was assented.

Carers NSW calls on the NSW Government to review the *Carers (Recognition) Act 2010* in 2014 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.

## 2. Transition to NDIS

In preparation for the full rollout of the National Disability Insurance Scheme (NDIS), significant reform is underway in the NSW disability sector. In the Hunter trial site for the NDIS and across the rest of NSW under *Ready Together*, more and more people with disability and their carers are gaining greater choice and control through person centred and individualised support models.

Carers NSW strongly supports this shift, which is already changing many lives for the better. However, this is also a period of considerable change, adjustment and uncertainty for carers, along with those they care for and their service providers. Adequate measures in the NSW Budget 2015-16 will be critical in laying the foundation required for a successful rollout of the NDIS across the state from July 2016.

### 2.1 Information and capacity building

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

3. Fund more targeted information, resources and training opportunities to prepare carers to engage with *Ready Together* and the NDIS.

Data from the Carers NSW 2014 Carer Survey indicates that awareness among carers of person centred approaches and individualised funding has increased since 2012<sup>1</sup>. This is probably largely owing to:

- increased exposure to these methods of service delivery in the NDIS trial site and under *Ready Together*
- NSW Government capacity building initiatives such as *My Choice Matters* and the *Getting Prepared* workshops, and
- efforts by Carers NSW and other organisations to inform carers about system changes.

However, a significant proportion of respondents to the 2014 Carer Survey had still not heard of person centred approaches and individualised funding<sup>2</sup>, demonstrating the need for further targeted information for carers. Carers NSW has also heard from carers and service providers that many carers are feeling confused and underprepared for engaging with changes under *Ready Together* and the NDIS.

***'There needs to be carer training to enable us to greater identify needs, plan and advocate for services. There is a danger that those most vulnerable will still not receive services and may become overwhelmed by excessive administration in the processes of choice and advocacy.'***

Carers NSW and others have found that the more prepared carers are for engaging with the person centred planning, individualised funding models and self-managed supports the better the outcomes are for the carer and the person they care for<sup>3</sup>. Carers have told us they want to know more about:

- how person centred approaches and individualised funding packages work
- how to access them
- how they will impact their current circumstances
- what they need to do to prepare
- where they can get support.

Greater, more targeted information, resources and training opportunities that are accessible and appropriate for diverse groups of carers will ease their anxiety about the changes to the disability support system and assist them to adequately prepare and secure positive outcomes for themselves and the people they care for.

Surveys of Carer Representatives and Carers NSW staff in May 2013 revealed that information on the following topics would be most beneficial for carers:

- what person centred approaches, individualised funding and person centred planning are
- comparison of different options for funding packages and management models
- information on managing funding
- information on decision making, navigating the system and choosing service providers
- information on hiring and managing staff (where applicable)

- information about the role and entitlements of carers in relation to person centred approaches.

As well as information, carers will require interactive training which gives them an opportunity to develop and practice relevant skills. Our survey findings and experience in delivering training have shown that resources and training should address the following areas:

- the role and rights of carers in person centred approaches and individualised funding, especially in relation to person centred planning
- self-advocacy to ensure carers needs and rights are addressed
- skills development in relation to managing a budget
- skills development in relation to recruiting and managing staff
- capacity building in relation to informed decision making and conflict resolution.

We recommend that funding be allocated to new and existing training courses specifically for carers. Non-government organisations like Carers NSW already have expertise in the delivery of this training and would be well placed to provide training to carers.

## 2.2 Support and advocacy

**Carers NSW recommends that the NSW Department of Family and Community Services:**  
4. Fund more individual support and advocacy for carers.

Carers not only require skills and information but also practical support and advocacy to negotiate the shift to individualised funding under *Ready Together* and the NDIS. Carers and service providers have particularly highlighted the importance of guiding ageing parent carers through the changes<sup>4</sup>.

The NSW Government has recognised the need of people with a disability for advocacy services, and funds the NSW Advocacy Program (disability) to meet this need. This program and the National Disability Advocacy Program are critically important. However, disability advocacy services have limited resources, and this has become especially apparent in the NDIS trial site, where some families have struggled to get adequate support.

Existing advocacy services are also not focused on carers' support and advocacy needs. Carers can only access advocacy funded through these and other programs when they are acting on behalf of the person they care for, not when they are acting on their own behalf. The need for carer advocacy services has been widely recognised<sup>5</sup>. Carers NSW believes the best option

***'A "case manager" is an absolute must to help navigate the world of support services. But NOT someone who simply gives you a folder of flyers and phone numbers'***

***'As ageing parents individualised funding is another 'problem' to tackle & sort through. An advocate to assist with paperwork, applications, & knowing what is available etc is needed.'***

would be for the NSW Government to develop a separate NSW Carer Advocacy Program to extend access to carers of people without disability.

Carers NSW experience delivering the Support Coordination Program for Older Parent Carers and the *My Plan, My Choice* older carers project has also shown that some carers, particularly those who have been caring for long periods of time, need personal support to be able to make informed decisions. In the *My Plan, My Choice* project conducted by Carers NSW, carers have received this assistance from a support planner and a support intermediary. Many carers would benefit from this kind of assistance to plan, understand support options and arrange appropriate support for themselves and their loved one. Carers NSW believes that this support should be available for all carers when they need it. The uncertainty about ongoing funding for the *My Plan, My Choice* project is also of concern.

Given the changing environment, increased and specialised advocacy funding is critical. Independent, individualised support for people with disability and their families and carers to work through preparation for person centred planning and individualised funding should also be funded in 2015-16 in preparation for the beginning of the full rollout of the NDIS in 2016.

### 2.3 Carer-aware service provision

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

5. Fund the development and delivery of carer awareness training for service providers and staff to support inclusion of carers.

The NSW Carers Charter<sup>6</sup> affirms the importance of carer recognition and inclusion in the assessment, planning, delivery and review of services provided to people with support needs. The principles of the Charter dictate that the contribution, knowledge, needs, interests of carers and their right to have a say in their caring role, should inform all stages of the process.

Carer recognition and inclusion in the assessment, person centred planning, support delivery and plan review of people with support needs benefits both the person and their carer<sup>7</sup>. We therefore recommend that the staff of person centred and individualised programs, such as Ability Links, be required to undergo carer awareness training. Carer awareness training is often provided by Carers NSW to service providers and government agencies.

***'I think BOTH carer and the cared for should be involved in the decisions, as both are affected.'***

Carer awareness will be particularly important for staff undertaking assessment, support planning and local area coordination functions, as they will be working directly with carers and need to develop an understanding the impact of the caring role, from the carer's perspective.

Given that carer inclusion can be hindered by service professionals' lack of understanding and skills in working collaboratively with family and friends,<sup>8</sup> staff training should also equip assessors, planners and coordinators with the practical skills required to engage people's

support networks, consider their needs and interests and carefully negotiate tensions that may arise between carers' rights and choices, and the rights and choices of the person for whom they care.

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

6. Implement formalised carer assessment as part of person centred planning and assessment processes used under *Ready Together*.

A key way to include carers is to provide a formalised carer assessment, separate to that of the person with disability, which takes into account the carer's own goals and needs. It should also assess whether a carer is able and willing to continue caring at the current level. Carer assessment was recommended by the Productivity Commission in its final report on the Disability Care and Support Inquiry and was highlighted in the Commonwealth *Who Cares...? Report*.<sup>9</sup> This kind of carer assessment is an entitlement in the UK, regardless of whether the care recipient undertakes an assessment for person centred social care.

Carers NSW therefore recommends that the NSW Government direct resources toward supporting service providers to consistently implement carer assessment, as well as the promotion of this opportunity to carers. We suggest that the NSW Government makes clear provisions for carer assessment, which will embed it as a formal process. These provisions should make it clear that carer assessments should be considered in conjunction with assessments made with the care recipient, and inform a holistic planning process.

## 2.4 Continuity of support

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

7. Ensure that service provision and quality are not disrupted by staffing changes related to the devolution of ADHC.

Many carers have expressed their trepidation about the devolution of Ageing, Disability and Home Care (ADHC) to the non-government sector by 2018, including the recently announced privatisation of Home Care and the loss of government as the provider of last resort<sup>10</sup>. In particular, some carers have reported that the disability services they currently receive are being adversely affected by the devolution of ADHC because of associated dissatisfaction and turnover of support staff.

### Case Study

Sonia's son Derek has Down Syndrome and lives in community housing with the help of a housing and support package. In recent months there has been a lot of changeover with staff in the organisations that support him due to changes occurring in preparation for the NDIS. This has been very disruptive to her son's care and has created a lot more work for her.

Similar concerns have recently been raised in the media by the Federal Assistant Minister for Social Services, Senator Mitch Fifield<sup>11</sup> and the Chairman of Federal Parliament's Joint Standing Committee on the National Disability Insurance Scheme<sup>12</sup>, warning of the importance of continuity of support in state services prior to the NDIS rollout.

**Carers NSW recommends that the NSW Department of Family and Community Services:**  
8. Plan ahead to ensure that money remains within FACS to address service gaps for people with disability and carers not covered by the NDIS.

In addition, there is a big question mark over what, if any, funded services will be available for people with disability who are not deemed eligible for the NDIS once the NDIS rolls out. The NSW Government will completely withdraw from providing and funding disability and community care supports from 2018, with the NDIS expected to take on this role.<sup>13</sup> The NDIS will provide disability supports to 140,000 people<sup>14</sup> under 65 in NSW with permanent and significant disability, and people with severe and persistent mental illness in limited circumstances<sup>15</sup>.

However, there are 437,600 people under 65 with a reported disability in NSW who need assistance with at least one activity<sup>16</sup>, not to mention the thousands of other NSW residents with a mental illness in need of support.

In the quarter ending 30 September 2014, the ineligibility rate for people requesting access to the NDIS in the NSW trial site was 14%<sup>17</sup>. This leaves large numbers of people with support needs who will not be eligible for the NDIS, and at this stage no planned funded supports for them. It also means that many people currently receiving support may lose it.

The *Ability Links* program has been set up to support people in NSW who are not eligible for the NDIS – either due to location, for those outside the trial site, or due to other eligibility criteria within the trial site. It provides a valuable time-limited service helping people with disability, their families and carers to make connections with supports in mainstream services and the community.

However, *Ability Links* does not prioritise linking people to specialist disability services, and does not have any funding to provide services, programs or case management for people with disability or their families and carers, regardless of their level of need. *Ability Links* will therefore not meet the support needs of people not eligible for the NDIS once it is fully rolled out. Additionally, as an ADHC funded program, it remains unclear whether it will continue after 2018, and if not, whether its role will be replicated under the NDIS.

***'None of it will make the slightest difference to our situation because our daughter is too independent to fit the official definition of supported disability... Yet, this doesn't change the reality that she still needs support.'***

***'As long as we don't fall through the cracks yet again and are eligible to get it then it would be so much better!!!'***

At the same time, many users of NSW funded disability services are starting to be transitioned to more individualised arrangements to prepare them for the NDIS, with some already reporting a reduction in the services they receive as a result of new, supposedly more person-centred assessments. If people with disability or a mental illness experience a reduction in or complete loss of supports and services in the transition to the NDIS, their friends and relatives, many of whom are under pressure already due to existing service gaps, will be forced to fill in the gaps and may be worse off as a result.

#### **Case Study**

Amy's brother Nick was part of ADHC's High Needs Pool and received 90 hours of home care per month. He was recently moved to the new Community Support Program and had an assessment to decide his individual budget. The new budget was supposed to cover home care, modifications, continence pads, and respite, but it is not enough money to even cover 60 hours of home care per month, let alone anything else. Amy, who can't work because of her caring role, was barely making ends meet before. Now they are \$200 a week worse off.

The NSW Government should also ensure that carers of people with disability continue to have access to the services and supports that they need in their own right. 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. The devolution of ADHC and complete redirection of NSW disability funding into the NDIS from 2018 assumes that the NDIS will take over ADHC's role in providing all disability supports.

However there is no guarantee that equivalent carer specific supports and services to those currently funded by ADHC will be covered under the NDIS. The NDIS is focussed on the support needs of eligible people with disability not carers, and while the supports provided will most likely benefit carers in some way, the scope of funded support for carers within an NDIS package is limited. This limited avenue for support will not even be available for carers who care for someone who is ineligible for the NDIS<sup>18</sup>.

Carers NSW is concerned that serious gaps may emerge in carer supports and services, especially following the full rollout of the NDIS in 2018. These must be mitigated as soon as possible so that no carer will be worse off.

### **3. Ageing parent carers**

#### **3.1 Ageing parent carers need extra care**

**Carers NSW recommends that the NSW Department of Family and Community Services:**  
9. Continue the Older Parent Carer Support Coordination (OPC) Program after the full roll out of the NDIS.

As noted in the previous section, Carers NSW is particularly concerned about the needs of ageing parent carers, many of whom have been caring for their adult son or daughter for decades, and who need support themselves as they age. Ageing parent carers are older people who are caring for their adult sons or daughters with a disability, mental illness or other condition. Although caring be a deeply rewarding experience for carers, it can also negatively impact every aspect of carer's lives, including:

- Poor health and wellbeing due to high levels of stress and anxiety, lack of sleep, social isolation and the physical demands of caring (e.g. back injury from lifting)
- Financial disadvantage due to the difficulties of engaging in paid work, alongside a higher cost of living with expenses such as medication, equipment, continence aids and services
- Fear for the future – who will care for their son or daughter when the carer can no longer keep caring?<sup>19</sup>

The Older Parent Carer Support Coordination (OPC) Program helps this particular group of carers manage these challenges and plan for the future. A report by the Anglicare Diocese of Sydney, also a provider of the OPC program, found positive improvements in carer wellbeing and service access and support for participants.<sup>20</sup> Carers NSW has heard from carers who greatly appreciate the support they have received through the program which, depending on the provider and each individual situation can include case management, social activities, IT training, presentations from service providers and ongoing support.

As the NDIS expands, the NSW Government will be withdrawing from funding disability services. However, the Older Parent Carer program is a specialised service which will not be possible to replicate in the NDIS, where the focus is people with a disability rather than carers. Research by Carers NSW with carers and families in the Hunter NDIS trial site found that many carers felt they were not considered in the planning process, and that they themselves have been left worse off.<sup>21</sup> While they are pleased that their family member with a disability may have improved support, the carer may find that they have lost access to respite care, transport, support groups and other valuable services. Therefore it is essential that the OPC program be continued, even after the full roll out of the NDIS, to ensure that ageing parent carers are supported.

#### **Case Study**

Karen is a widow caring for two adult daughters with disability. Karen has found caring more difficult now that her husband has passed on and she is getting older with health issues of her own. She has benefited greatly from the Older Parent Carer Program, especially the social events and IT training, however Karen is worried about what will happen when the program is phased out with the NDIS.

*'Who will care for the carer? Don't forget us. We were already forgotten, and then were grateful for the support we got under the Older Parent Carer Program. We don't want to be*

### 3.2 Support for all ageing parent carers

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

10. Expands the Older Parent Carer Support Coordination (OPC) Program to reach more 'hidden carers'.

While the OPC program provides valuable support to ageing parent carers, there are many 'hidden carers' who, while eligible for the program, are not receiving support. Therefore, the OPC program needs additional resources and a renewal of the program guidelines to ensure that all ageing parent carers can be offered support. While the program is well funded in terms of the support packages for clients, operationally the program needs increased funds in order to employ more support coordinators.

While Aboriginal people are more likely to be caring for a family member with a disability or illness, they are less likely to be recognised as a carer and receiving support. This can be for a range of reasons including cultural understandings of disability, care and family, difficulty accessing services in isolated areas and lack of culturally appropriate services. One OPC worker explained that traditionally, Aboriginal communities don't recognise the concepts of 'carer' and 'disability' in the same way as mainstream communities. This means that despite the challenges, Aboriginal carers are much less likely to seek support in their caring role, making it much harder for the OPC program to reach this group. In her experience, it is common for Aboriginal ageing parent carers not to be receiving any support prior to joining the OPC program. Carers from CALD communities also face barriers to accessing support, including lack of awareness of services and language difficulties.

Many ageing carers of an adult son or daughter with a serious mental illness could also benefit from the program, however for a number of reasons they often miss out. These include a lack of clarity regarding whether or not carers of people with a mental illness meet the eligibility guidelines, as well as the stigma surrounding mental illness. This can lead to social isolation for people with mental illness and their families, and a reluctance to seek help for themselves or family members.

The OPC program needs more funding so that they can reach out to these 'hidden carers' – people who might not see themselves as carers, but who share the same challenges. This would ensure that OPC workers can connect with all ageing parent carers, build a respectful relationship and offer support that will make a meaningful difference to their lives and the lives of the people they care for.

## 4. Carers in our health system

The sustainability of the NSW healthcare system depends on the contribution of unpaid carers. Carers have been described by the National Health and Hospital Reform Commission as the

“invisible health workforce” in acknowledgement of their critical and often unrecognised role as the major providers of care in the community.<sup>22</sup>

***‘Would like to see put in place an “integrated package” put in place when someone is diagnosed with a major mental illness and other illnesses. Not left to Carer to struggle to find the support and help!’***

The need to focus on carers was acknowledged in the NSW Government’s *NSW State Health Plan: Towards 2021*, which articulated an ambitious but achievable vision for the NSW health system. Carers NSW welcomes its focus on keeping people healthy, excellence in clinical care and delivering integrated care, and our recommendations address how carers can be considered within all these areas.

Carers NSW also notes that the *NSW Carers Strategy 2014-2019* identified a range of projects which aim to improve the health and wellbeing of carers, their capacity to easily access health care and their experiences in the health system overall.

Across NSW, Carer Support Services are already doing important work within their Local Health District to create health systems which are more responsive to the needs of carers.

The Strategy provides an opportunity to harness the successes of Carer Support Services and embed carer inclusiveness across the whole health system through innovations such as the TOP 5 project. Carers NSW looks forward to our involvement in these projects, and working together with the NSW Government to deliver better outcomes for carers in our health system.

#### **4.1 Integrated care for carers**

**Carers NSW recommends that the NSW Ministry of Health:**

11. Ensure that LHD Demonstrator Sites, and programs funded through the Integrated Care Planning and Innovation fund:

- Include carers as partners in care
- Report on outcomes for carers.

In 2014 Carers NSW welcomed the release of the *Integrated Care Strategy 2014-2017*, and the Government’s significant funding commitment to see the *Integrated Care Strategy* turn into action. Carers NSW has consistently championed integrated care, and believes the *Integrated Care Strategy* presents a great opportunity for carers journey through the health system to be improved. Integrated care puts patients and their support network at the centre of service planning, and provides an opportunity for carers to be genuinely included as partners in care.

Carers NSW is very keen to see integrated care activities delivers outcomes for carers, and we insist on carers being identified as a key stakeholder across all trial sites and funded projects. In order to for us to know that the *Integrated Care Strategy* is truly delivering for carers, Carers NSW advises that outcomes for carers, not just consumers, are reported on. Carers must be embedded in ongoing evaluation of integrated care activities, and their experiences must be

routinely collected. The state wide enablers of integrated care will be crucial in achieving this goal, as they have the capacity to facilitate the identification of carers, and collect information about carer experiences as integrated care is rolled out across NSW.

#### 4.2 Carers voice in the health system

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

12. Fund the development of tailored training and ongoing support for carers to 'have their say' in the health system.

There is increasing recognition that in order to deliver world class, patient-centred health care the voices of consumers and carers must be listened to and acted upon. Whilst the release of a state wide *Consumer and Community Engagement Framework* has stalled, engagement of consumers and carers has been identified as a priority within the *NSW State Health Plan*, and by Local Health Districts. This priority is consistent with Standard 2 of the *National Safety and Quality Health Service Standards*, which requires health services to actively partner with consumers and carers to improve the safety and quality of care.

Within the *NSW Carers Strategy*, **Project 4.3: Engaging carers in local decision making** refers to the need to better engage carers in decision making about policies and programs which affect them. As NSW Health services are increasingly seeking the input of carer representatives, Carers NSW considers it appropriate that this project consider how carers can better engage with local health services.

As a member of a number of carer focused committees which drive improvements in carer recognition, inclusion and support within health services, Carers NSW has seen firsthand the positive outcomes that result from involving carers in service delivery. Carers NSW also manages a Carer Representation Program, which supports Carers NSW Carer Representatives to participate in activities including within the health system and is aware of the benefits of carer representation, as well as the challenges.

There are a number of barriers to carer engagement in decision making in the health system, including the complex structures and processes within NSW Health services. The Consumers Health Forum of Australia has noted that:

*'One of the most prevalent approaches to consumer participation in Australia is the appointment of a consumer representative on government committees... However, the consumer is often a lone voice amongst many health care professionals, service providers, industry and government representatives. Consumer representatives need access to training and support in order to be effective in influencing committee outcomes, and in dealing with the unfamiliar culture and practices of professional committees.'*<sup>23</sup>

Carers NSW concurs with this assessment, and we affirm the need for consumers and carers to have opportunities to develop their knowledge and skills, and access ongoing support, in order

to participate effectively and maximise their influence in unfamiliar systems. While Carers NSW is able to provide general training in areas such as communication skills and systemic advocacy, the Carer Representation Program lacks the resources to train carers in the specific knowledge and skills required to navigate the health system.

*'Even though I felt like I 'knew the system' possibly better than others, I was still intimidated by it....'*

Carer representative within NSW Health

Carers NSW notes that whilst these opportunities often exist for health consumers (which may be inclusive of carers) it would be beneficial for these opportunities to be tailored to the particular needs of carers. Carers and consumers have independent perspectives and represent different interests, and the unique nature of carers experiences and perspectives should be recognised and respected. Too often carer representatives are confused with, or given the title of, consumer representative, and Carers NSW believes this undermines their role as representatives of carers and the unique expertise they have as carers.

Carers NSW suggests that existing models of health consumer representative and general carer representative education, training and support could be built upon, in order strengthen carers capacity to 'have their say' in the health system.

### 4.3 Keeping carers healthy

#### **Carers NSW recommends that the NSW Ministry of Health:**

13. Take action to keep carers healthy, by:

- Ensuring existing preventative health programs are community based and easily accessible by carers
- Identifying opportunities for promoting and targeting preventative health initiatives to carers.

Carers NSW encourages the NSW Government to take action to address carers reduced health and wellbeing through preventative health initiatives. Whilst carers are not identified as a high risk group within the *NSW State Health Plan*, Carers NSW suggests that there is significant evidence to suggest that we need to be doing a lot more to keep carers healthy.

Carers need health services that are flexible, health professionals who ask about their wellbeing and who make it easy for carers to get some of their own health needs met at the same time as those they care for. As a key partner in the *NSW Carers Strategy*, Carers NSW strongly supports building on and expanding existing health screening and intervention programs such as community based health check programs (e.g. pharmacy health checks) that are easily accessible and promoted to carers.

It is well established that carers experience reduced physical, mental and emotional health. Australian studies have shown that carers have an average rating on the depression scale that

is classified as moderate depression, are more likely to be experiencing chronic pain or carrying an injury associated with caring, and are more likely to report high blood pressure and high cholesterol when compared to non-carers.<sup>24</sup> Carers have a significantly higher incidence of chronic diseases, and are at least 40 per cent more likely to suffer from a chronic health condition than the rest of the population.<sup>25</sup>

Carers NSW 2014 Carer Survey confirmed what we already know about carers health and wellbeing- that carer wellbeing is poor compared to the general Australian population.<sup>26</sup> The Survey also revealed that carers with a long-term illness or disability experience particularly low wellbeing across all measures, compared to those without an illness or disability.<sup>27</sup> It found that the prevalence of carer illness and/or disability increased as the length of time they had been caring increased- a trend which was more significant than the increase in illness and disability you would expect as carers grow older. It was also concerning to note that, in addition to poorer wellbeing outcomes, carers with a long-term illness or disability reported less social support and more barriers to accessing formal support services.

These findings highlight that the toll of caring accumulates over time, and impacts carers health beyond typical ageing related health issues. Considering the poor health outcomes associated with caring, especially caring over an extended period, Carers NSW calls upon the NSW Government to assist carers to maintain optimum health and wellbeing. Carers NSW recommends that this can be achieved by targeting existing initiatives of the NSW Office of Preventative Health to carers, but we encourage the NSW Government to take even further action to prioritise carers. Carers NSW recommends that the NSW Government build on existing partnerships with carers and key stakeholders to design and promote preventative health initiatives with and for carers, that addresses their unique needs.

#### **4.4 Effective investment in community mental health**

**Carers NSW recommends that the NSW Ministry of Health:**

14. Increase investment in carer inclusive community-based mental health services.

Numerous reports into Australia's mental health system have highlighted the need to shift investment from the acute end of mental health services towards early intervention, prevention of crises and maintenance of health and wellbeing based on recovery principles. However carers of people with a mental illness continue to report to Carers NSW that the person they support is unable to access services because they are not unwell enough or not currently experiencing a crisis. As NCOSS has noted, NSW has relatively low spending on mental health, and low spending on community-managed mental health compared to other states and territories, and our system tends to focus on hospital-based care.<sup>28</sup> NCOSS has pointed out that this leads to people cycling in and out of hospital due to lack of appropriate support. Inadequate support for consumers and carers not only hinders consumers' recovery, but can also have a detrimental impact on carers own mental health, placing further strain on an already over-stretched system.

Carers NSW advocates for the NSW Government to deliver support to people with a mental illness and their families and carers in their communities, well before they reach breaking point. We recommend that the NSW Government grow their investment in community supports that operate using recovery focused, family/carer centred models in which carers of people with mental illness are identified as ‘partners in care’.

The need to increase investment in community-based supports is especially important as NSW moves towards the NDIS. There remains confusion and lack of clarity about what services people will receive if they are not eligible for an individual support package under the NDIS. As discussed in Section 2, Carers NSW particularly concerned about the capacity of the NDIS to meet the needs of carers and notes that support for carers in and of their own right must be funded into the future, either as part of the NDIS, or independent of it.

***‘To regularly attend a carer support group updating us what is happening in the sector would be good, but it is difficult for me to transport my husband in wheelchair to get there. And taxis are very costly for us.’***

We call upon the NSW Government to show leadership in this area, by increasing expenditure on mental health, and focusing this investment in community-based mental health services.

## 5. Carers and transport

People travel to visit friends and family, to commute to work and take children to school or childcare. People use public and private transport to go shopping, to travel to work meetings and for medical appointments. Transport is integral to many functions of everyday life, and the NSW Government has recognised this by maintaining a strong focus on transport during its two and half years in Government. Carers NSW welcomes that the 2013-14 Budget contained a record investment in new transport projects which, along with the release of the *NSW Long Term Transport Master Plan*, demonstrate that the NSW Government is committed to delivering on its promises.

There is no doubt that having access to transport is an important issue for carers across the state. In 2012 there were 306,200 people with a disability in NSW who required assistance with transport, and 91 % per cent those who received assistance received it from informal carers.<sup>29</sup> Around 17.5 per cent of people in NSW over the age of 65 needed assistance with transport, which was overwhelmingly provided by carers.<sup>30</sup>

Transport affordability, the accessibility of buses, train stations and taxis and the frequency of services can all impact upon carers’ ability to travel. However carers continue to report to us that they experience difficulty accessing transport that meets their needs and the needs of the person they care for. Carers and the people they care for are vulnerable to transport disadvantage, which renders services inaccessible, entrenches social isolation and negatively impacts upon participation in employment and education and health and wellbeing. There is

also growing evidence that there is a strong link between transport, disadvantage and social exclusion.<sup>31</sup>

As in previous budget submissions, our recommendations continue to focus on the improvement of the transport system so that it is more equitable, and will promote positive outcomes for carers and the people they care for.

Better transport provision and accessibility will not only reduce the transport stress experienced by many carers, it will also improve the accessibility and usefulness of services which carers utilise, such as respite. This will be particularly important in the transition to person centred packages, to ensure that carers and people with a disability can access the available options. The time, cost and stress involved in transporting care recipients, whether it is crossing peak hour traffic in a metropolitan centre, or great distances in rural NSW, compromises the potential benefits of using this service. Having a strong transport system which meets carer's needs will positively benefit carer's health and wellbeing.

### 5.1 Taxi Transport Subsidy Scheme

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

15. Raise the subsidy cap for the Taxi Transport Subsidy Scheme to \$60 per trip.

The Taxi Transport Subsidy Scheme (TTSS) entitles people with severe and permanent disability to a half rate concession of the prescribed taxi fare, up to a maximum subsidy cap of \$30 per trip. This subsidy cap has not been increased since 1999, although taxi fares have increased by more than 60% over this period.<sup>32</sup>

Both formal and anecdotal evidence<sup>33</sup> indicates that carers and the people they care for are using wheelchair accessible and/or other taxis less frequently due to cost. Transport for NSW's (TfNSW) TTSS consumer study conducted this year demonstrates that lack of affordability is a major barrier for people with disability using the TTSS. These findings reveal that the subsidy cap only allows people to take very short taxi trips, and even with short trips affordability is still an issue.

As explained in our previous budget submission, the current cost of taxis is prohibitive to carers, who are more likely to be financially disadvantaged than non-carers. Therefore, Carers NSW again calls to increase the subsidy cap to \$60 per trip in order to align the scheme with other jurisdictions and with the increase in taxi fares over the last decade.

### 5.2 Access to health services for rural and regional carers

**Carers NSW recommends that NSW Ministry of Health:**

16. Strengthen its commitment to improve transport for health across NSW (especially in rural and regional areas) by providing details about how it will fund, implement and evaluate this goal within the next 2 years.

With increasing numbers of older people living in regional areas, demand for community and public transport is on the rise, and will significantly increase in the longer term. Carers living in regional areas frequently identify a lack of transport and local services as one of their main concerns.

Patients and their carers often have to travel long distances to access the health services in regional centres or relocate to metropolitan areas for lengthy periods of specialist treatment. This can lead to severe financial pressure as families struggle to meet the costs of accommodation, travel and treatment while also facing the loss of paid employment.<sup>34</sup>

***'I live on a rural property out of town. No transport other than my own car. Transport services very limited and hard to get into.'***

Relocation can also mean that patients and carers are isolated and removed from informal support networks such as extended family and the community.

Therefore, Carers NSW welcomes NSW Health's commitment to improve the access to health transport for people living in rural and regional NSW as stated in the recently published *NSW Rural Health Plan 2014*. We are especially pleased about the plan's initiative to 'further promote access to the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)' as this was one of our recommendations in our latest budget submissions. Additionally, we commend NSW Health subsequent two goals to 'work with government service providers to streamline access to IPTAAS for GPs and patients' as well as 'Work with community transport providers and Transport for NSW to improve transport services'.<sup>35</sup>

However, Carers NSW is concerned that the *NSW Rural Health Plan* lacks detail about how the goals and initiatives regarding improved access to health transport will be achieved; in particular how they will be funded, implemented and evaluated. We therefore recommend that the Ministry of Health not only plans to work with community transport providers, Transport for NSW and other stakeholders but also provides details on how and when this important goal will be met.

### **5.3 Community transport provision**

**Carers NSW recommends that Transport for NSW and the NSW Ministry for Health:**  
17. Increase their funding share of Community Transport providers to meet the growing need for non-emergency transport to health services across NSW.

Appropriate and accessible transport acts as a significant enabler to access health services. Inadequate transport options can mean that people are unable to get preventative treatment, receive effective care or a diagnosis in a timely manner. Carers are at risk of transport difficulties due to high rates of socio-economic disadvantage. The need for non-emergency health transport services is significant and growing.

Carers NSW commends the work to date by the Community Transport Program (CTP) which offers non-emergency transport to people who are unable to travel by car or public transport,

with a strong focus on providing services for older people and people with disability. This includes activities such as shopping, transport to day-care, outings, and health related transport. As CTP has a relatively broad focus, the program has the capacity to assist carers and care recipients who most need the services and are unable to access other forms of transport.

*'I drive my friend to a medical exercise clinic twice a week. The local community bus only goes once a day and is booked months in advance by regulars. Other voluntary agencies are not always reliable as they depend on volunteers.'*

However, community transport providers have been facing the challenge of managing increasing demand for health related transport with more than 798,000 trips for health related purposes in 2013-14. Many providers cannot meet the rising demand and are routinely forced to refuse requests for transport to health treatment, with some services excluding health related transport from their services because they do not have the resources to meet demand. Health related transport is increasingly using a greater proportion of community transport providers' budgets and has become the main focus of transport by volunteers in rural areas, although still not being able to satisfy the current demand. Almost one third of community transport trips are for health purposes, but NSW Health provides only 3% of community transport funding.<sup>36</sup>

Therefore, Carers NSW believes that additional funding for Community Transport providers would enable them to renew their focus on community members who experience transport disadvantage, while still meeting some of the demands for health transport.

## 6. 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 priority areas for carers in NSW, and we urge the NSW Government to consider our recommendations.

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.

## Endnotes

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