



## **Putting Carers First**

**Carers NSW Pre-Budget Submission  
2017-18**

**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

## ABOUT CARERS NSW

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

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

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

[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 the care they provide 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

Anyone working with carers will tell you that carers routinely put themselves last. Of first importance to a carer are the needs of the person(s) they care for, and meeting these needs often comes at the cost of the carer's own health and wellbeing.<sup>1</sup> Any time and energy carers have to spare will usually be spent on their immediate family or fulfilling responsibilities such as paid employment.

A carer's own needs – whether for time out, health care, exercise, sleep or meaningful time with loved ones – are often so far down the list that they may never be met. Indeed, carers have been reported to have the lowest wellbeing of any group in Australian society.<sup>2</sup> Often caring for more than 40 hours per week,<sup>3</sup> many carers neglect their own health care,<sup>4</sup> face social isolation<sup>5</sup> and forego employment opportunities and their associated financial and social benefits<sup>6</sup> in order to fulfil their caring responsibilities.

When a carer's health suffers, or a caring relationship is no longer sustainable, the cost to the health and/or disability sector can be significant. For example, one carer may neglect to treat their chronic health condition(s), such as back pain, resulting in preventable complications,<sup>7</sup> while another carer may relinquish the person they care for into expensive hospital or residential care because they can no longer cope to have them at home.<sup>8</sup> Sustainable health and disability funding therefore relies on adequate, preventative carer support. Indeed, the 857,200 carers in NSW<sup>9</sup> saved governments an estimated \$17.7 billion in 2015 alone.<sup>10</sup>

In order to look after their own health and wellbeing, carers need information, support and time away from the caring role. They also need to know they are a carer and that support is available. While family members and friends can provide some of the support carers require, many carers rely on funded services to achieve these objectives. The Carers NSW 2014 Carer Survey reported that 43 per cent of respondents had nobody else to help them care, while around one third of respondents indicated that there was nobody they could call on for help if they were ill or needed a break.<sup>11</sup>

The NSW Government has a strong history of supporting carers. The enactment of the *NSW Carers (Recognition) Act 2010* (the Act) and accompanying *NSW Carers Charter*, currently undergoing review, enshrine key principles of carer recognition, engagement and support that have shaped the trajectory of Government services in our state. An ongoing commitment to increasing awareness of, and compliance with, the Act across the public sector will be critical in raising the profile of carers in NSW, promoting carer identification and conveying the message that carers can, and should, look after themselves.

The launch of the *NSW Carers Strategy 2014-2019* (the Strategy) in 2014 further demonstrated the Government's commitment to recognising and supporting carers, and has since produced a range of positive outcomes for diverse groups of carers across NSW. The delivery of the 2017-18 State Budget will mark the halfway point for the delivery of the Strategy, and while much has been achieved, there is considerable room for expansion.

In order to sustain the invaluable caring arrangements that supplement our health and disability services, the NSW Government must continue to ensure that carers' needs are a matter of priority, and not relegated to an afterthought following the needs of the persons they

care for, as has often been the case in the transition to the National Disability Insurance Scheme (NDIS).<sup>12</sup>

This Pre Budget Submission focuses on four key areas that Carers NSW has identified as of the most importance to address for carers in the 2017-18 State Budget. These are:

1. Delivering the NSW Carers Strategy
2. Supporting carers in our health system
3. Supporting mental health carers
4. Transition to NDIS

Our recommendations, developed in consultation with our staff, carers and key partners and stakeholders, highlight what we believe are the most achievable and cost-effective ways in which the NSW Government can make practical gains for carers in the 2017-18 financial year. Carers NSW urges the NSW Government to seriously consider these recommendations and commit to putting carers first in the 2017-18 State Budget.

## SUMMARY OF RECOMMENDATIONS

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

- continue to support and invest in the *NSW Carers Strategy 2014-2019* in order to maximise outcomes for carers (**Recommendation 1**)
- continue to fund Companion Card eligibility for NDIS participants but quarantine the program from NDIS transition (**Recommendation 15**)

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

- establish an statewide network connecting and resourcing Aboriginal carers and organisations across NSW (**Recommendation 2**)
- fund young carer specific mentoring under the Youth Frontiers Mentoring Program (**Recommendation 3**)
- commit further funding to expanding the potential of SkillsLink2Work (**Recommendation 4**)
- fund a contact phone number and regular e-newsletter to accompany its NSW NDIS website (**Recommendation 11**)
- maintain or delegate the status of provider of last resort (**Recommendation 12**)
- in partnership with Transport for NSW, ensure affordable community transport options remain for people with disability and their carers, regardless of their NDIS eligibility (**Recommendation 14**)
- fund an individual advocacy program available to all carers of people with disability throughout the NDIS transition period (**Recommendation 16**)

Carers NSW recommends that **NSW Health:**

- improve access to palliative care physicians and nurses across NSW (**Recommendation 6**)
- increase investment in onsite accommodation, carer-friendly wards and parking subsidies to recognise and enable the important role that carers play in the health care of hospital patients (**Recommendation 7**)
- provide dedicated nurses to conduct carer health assessments when carers accompany the person they care for in hospital or in primary and community health settings (**Recommendation 8**)
- fund a statewide education and awareness campaign to improve understanding of amendments to the NSW Mental Health Act 2007 among carers and health professionals (**Recommendation 9**)
- fund an evaluation of the Family and Carer Mental Health program and increase the funding allocated to the program in 2017-18 (**Recommendation 10**)

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

- prioritise increasing the frequency and variety of accessible public transport options in rural and regional areas (**Recommendation 13**)
- in partnership with the NSW Department of Family and Community Services, ensure affordable community transport options remain for people with disability and their carers regardless of their NDIS eligibility (**Recommendation 14**)

Carers NSW recommends that the NSW **Department of Industry:**

- extend eligibility for fee exemptions within the Smart and Skilled initiative to young carers (**Recommendation 5**)

## 1. DELIVERING THE NSW CARERS STRATEGY

Carers NSW is a key partner in the NSW Carers Strategy 2014-2019 (the Strategy) and has been actively involved in the ongoing development and delivery of a range of projects. We believe the Strategy represents a valuable, collaborative commitment to improving the lives of carers in NSW. However, as the Strategy reaches its halfway point, we would like to highlight the importance of ongoing leadership, innovation and targeted investment in relation to its focus areas in the 2017-18 financial year.

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

### 1.1 Aboriginal Carer Network

In our Pre-Budget Submission for the 2016-17 State Budget<sup>13</sup>, Carers NSW highlighted the importance of better connecting and resourcing Aboriginal carers across NSW in order to expand the reach of Aboriginal resources created under the NSW Carers Strategy.

Carers NSW believes that the usefulness of tools such as the updated *Taking Care of Business: Planning Ahead for Aboriginal in people in NSW*, developed under Commitment 3.4, will be limited if these are not effectively and widely distributed. A formalised structure or mechanism to facilitate engagement and consultation with Aboriginal carers would, we believe, facilitate this.

We therefore propose an Aboriginal Carer Network be set up for the life of the NSW Carers Strategy to complement work already being done to support Aboriginal carers. This Network could use a predominantly online platform to increase engagement, consultation and information sharing between Aboriginal carers and professionals working with carers in Aboriginal communities, expanding the reach of NSW Carers Strategy projects.

We recognise the limitations of internet based resources and networks, especially for carers over the age of 65, from low socio-economic backgrounds and living in rural and remote areas.<sup>14</sup> However, we believe engaging a broad range of stakeholders online would be limited in cost and would open up further opportunities for face to face engagement and consultation that would be valuable to the NSW Carers Strategy and the NSW Government as a whole.

*“Aboriginal/CALD Carers somehow have to find the courage to come forward and talk about the situation that they are enduring.” – Aboriginal carer support worker*

**2. Carers NSW recommends that the NSW Department of Family and Community Services establish a statewide network connecting and resourcing Aboriginal carers and organisations across NSW.**

## 1.2 Young carer mentors

In November 2014 a Young Carer Roundtable was held as part of the NSW Carers Strategy to coordinate action on young carers' access to existing youth mentoring programs. Carers NSW believes that programs recruiting and training mentors and tutors specialising in working with young carers should attract further investment from the NSW Government.

Young carers are more likely than their peers to experience socio-economic disadvantage and tend to achieve lower levels of education, impeding their ability to obtain adequate employment and potentially reducing their lifetime earning capacity.<sup>15</sup> Mentoring provides a valuable opportunity to support young carers to complete school and transition into tertiary education or employment.<sup>16</sup>

While generic youth mentoring programs like the Youth Frontiers Mentoring Program can achieve these objectives, young carers have expressed to Carers NSW staff that they would benefit most from mentors who understand the unique challenges they face and can also appreciate and reflect on the benefits of the caring experience.

*“There is still a lot of stigma surrounding mental illness and many do not realise how draining/difficult it can be to be a carer on top of everything else.” – Young carer respondent to Carers NSW 2016 Carer Survey*

**3. Carers NSW recommends that the NSW Department of Family and Community Services fund young carer specific mentoring under the Youth Frontiers Mentoring Program.**

## 1.3 Supporting carers to enter the workforce

Carers NSW commends the NSW Department of Family and Community Services (FACS) and partners on the development and launch of the SkillsLink2Work project and has received positive feedback from a number of carers. However, Carers NSW believes this program could be expanded to help carers better communicate and demonstrate their skills in applying for jobs.

The SkillsLink2Work tool currently takes carers through a series of checklists to identify what skills they use in their caring role. It then produces clear but comprehensive reports summarising these skills that can be used to acquire paid employment. However, Carers NSW notes that the tool does not provide output or advice about how to incorporate the reports into a job application. Furthermore, the reports themselves do not explain the tool, its context and its usefulness for prospective employers.

Carers NSW believes that SkillsLink2Work would be more effective if it provided additional support to carers wanting to promote their skills. This could be as simple as:

- updating the report template to include an explanation of what the tool is and why it is useful to employers
- creating an extra web page that explains how the report can be presented to potential employers, and/or included in application paperwork, including examples
- providing examples of cover letters and resumes where carers have drawn on these reports and placed them in context for potential employers

The tool could also help carers to create a complete resume using these skills, by translating them into a resume format that also prompts them to include relevant training, volunteering and paid work experience. Approximately 45 per cent of carers, and 60 per cent of primary carers, in NSW are not in the labour force.<sup>17</sup> Many carers remain outside the workforce for some time; for example, in 2016, over 80 per cent of people receiving the Carer Payment, had been receiving it for five years or more.<sup>18</sup> This can make applying for jobs a particularly daunting prospect.<sup>19</sup>

Some carers could also benefit from further, more personalised support as a result of using SkillsLink2Work. Via this platform, carers could be offered subsidised face to face career advice to give them greater confidence in applying for paid work.

*“Ideally I would like to and need to be gainfully employed - I am barely surviving financially and my financial situation is not sustainable...I have tried to re-enter the paid workforce but failed and am currently doing volunteer work so that I have a current reference person for applying to job ads in the future when I have gained some confidence back.” – Respondent to Carers NSW 2016 Carer Survey*

**4. Carers NSW recommends that the NSW Department of Family and Community Services commit further funding to expanding the potential of SkillsLink2Work.**

**1.4 Making vocational training more accessible**

The Smart and Skilled Initiative subsidises vocational training fees of people aged 15 to 30 who have left school and are living and/or working in NSW. Under this initiative fee-free scholarships and concessions are available to those who meet the eligibility criteria.

Currently, access to fee-free vocational training scholarships is available to those who have previously been in out-of-home care, people with a disability receiving the Disability Support Pension and their dependents, Aboriginal and Torres Strait Islanders and those that are currently experiencing, or have experienced, domestic violence.<sup>20</sup> Concession rates are also available to others receiving Commonwealth income support pensions (including the Carer Payment but not Carer Allowance or Carer Supplement) and dependents of people receiving these payments.<sup>21</sup>

While this initiative is yet to be evaluated at the time of writing, Carers NSW believes it is a positive way of assisting disadvantaged groups to build their marketable skillset. Fee-free scholarships could be extended to all young carers as an additional target group –

regardless of whether they are a dependent of a person receiving the Disability Support Pension – as they are known to face substantial educational and financial disadvantage, as detailed in Section 1.2.

Facing lower levels of educational attainment and fewer employment opportunities,<sup>22</sup> young carers are expected to have reduced lifetime earnings compared to their peers.<sup>23</sup> Consequently, many young carers rely on government pensions or allowances as a source of income.<sup>24</sup> Evidence indicates that once the caring role ceases, many young carers continue to require government supports,<sup>25</sup> making support to transition to work a critical priority for carers, even before their caring role ends.<sup>26</sup>

Extending eligibility of fee-free scholarships to young carers would contribute towards reducing the financial barrier that prevents many young carers from engaging in educational opportunities. Additionally, by assisting young carers to pursue vocational training, this would prepare young carers in their transition from the caring role into employment.

**5. Carers NSW recommends that the NSW Department of Industry extend eligibility for fee exemptions within the Smart and Skilled initiative to young carers.**

## **2. SUPPORTING CARERS IN OUR 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>27</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. Carers of people using health services should continue to be recognised, included and supported to navigate the system, wherever possible.

### **2.1 Improved palliative care support**

Carers of people receiving palliative care rely on the expertise and guidance of professionals to ensure that the person they care for spends their final days in comfort, dignity and in a setting of their choice. Palliative care professionals support continuity of care and enable carers to navigate the services required for end-of-life care in a complex and fragmented health system.<sup>28</sup>

The benefits of end-of-life intervention extend well beyond reduced hospital admissions and the patient's personal comfort. Evidence suggests that access to palliative care results in a significant increase in carer wellbeing, both in the short and long term. Carers have better physical and mental health outcomes and take less time to 'move on', returning to work and engaging in family and community life sooner.<sup>29</sup>

Carers NSW supports the Cancer Council's campaign to fund 10 additional specialist palliative doctors, 129 palliative care nurses and targeted provision of culturally appropriate palliative care for Aboriginal people. We believe that every person with a life-limiting illness who needs specialist palliative care should have access to it, when they need it, regardless of where they live.<sup>30</sup> Further investment in qualified palliative care professionals will ensure that more carers are supported and better equipped to provide end-of-life care at home and in the community.

Carers NSW also wishes to highlight the importance of adequately funding palliative care teams in local health districts and facilitating working connections between these teams, other local teams and the Palliative Care After Hours Helpline, to ensure timely and effective support for patients and carers in crisis.

*Geoffrey's elderly mother June was discharged from hospital to die at home. Two weeks after discharge, they had received no follow up support as promised. When June's condition worsened, Geoffrey called the Palliative Care After Hours helpline for advice. Neither the helpline nor the hospital were able to provide a current contact number for the local palliative care team. Another local hospital was sympathetic but merely referred him back to the helpline. Eventually June passed away, after a prolonged period of suffering without any professional support. The experience was very distressing for Geoffrey and not at all what he expected.*

**6. Carers NSW recommends that NSW Health improve access to palliative care physicians and nurses across NSW.**

## **2.2 Carer inclusive hospital facilities**

In our 2016-17 Pre-Budget Submission Carers NSW advocated for increased investment in onsite accommodation for carers supporting patients in hospital, especially those travelling from regional and rural areas. We would like to reiterate this recommendation, citing the importance of affordable, accessible onsite accommodation that enables carers to sustainably accompany their family member or friend on visits to hospital and thus contribute to their care.

Accommodation can, and should, take the form of purpose-built facilities in close proximity to the hospital itself, especially when longer term stays are required. However, hospital redevelopment also creates the opportunity to develop innovative, cost-effective alternatives for shorter stays.

For example, as part of the Blacktown and Mt Druitt Hospital expansion, 40 designated Carer Zones have been established within single patient rooms.<sup>31</sup> Carer Zones are a section of patient rooms, containing a curtain and bed and providing privacy and comfort to the carer whilst accompanying the person they are caring for. Due to this innovation, carers no longer have to sleep in a chair and are able to get restful sleep. In addition, carers are also provided with a 'carer card' to access discounted parking.

*Eleanor's husband Joe has quadriplegia and was admitted to hospital. There were not enough adequately skilled staff to deal with Joe's high support needs during his hospital stay, so Eleanor had to stay at the hospital to assist with moving and feeding him.*

Accommodating carers in hospital wards better enables carers to provide ongoing reassurance and emotional support to the person they care for, as well as assist with monitoring the person's condition and completing practical tasks such as feeding and showering. Furthermore, the benefit of subsidised parking recognises the important role of carers and the socio-economic disadvantage that carers often experience as a result of their caring role.

**7. Carers NSW recommends that NSW Health increase investment in onsite accommodation, carer-friendly wards and parking subsidies to recognise and enable the important role that carers play in the health care of hospital patients.**

### 2.3 Carer health checks

It is well established that carers are more likely than non-carers to experience reduced physical, mental and emotional health. Approximately one third of carers in NSW have a disability<sup>32</sup> and evidence suggests that carers are more likely to have a chronic health condition, report cardiovascular disease risk factors, be overweight or obese and experience chronic pain or injury as a result of caring.<sup>33</sup> Caring is also associated with anxiety, depression and psychiatric illness.<sup>34</sup>

In the UK, carer wellbeing assessments are conducted by nurses, healthcare workers and pharmacists in various sites throughout the country.<sup>35</sup> These assessments involve

*"Carers should also be a priority of primary health care services dealing with people with chronic conditions." – National Health and Hospitals Reform Commission (2009)*

physical health measures of non-communicable disease risk factors (such as BMI, blood pressure, cholesterol, blood sugar) and mental health assessments.<sup>36</sup> Carers NSW recommends that a similar approach be adopted in local health districts across NSW.

We propose that dedicated carer nurses be funded to operate in hospital settings, conducting carer health assessments while carers are accompanying the person they care for in hospital. These or other carer nurses could also operate in the community through GP practices, pharmacies and/or community healthcare settings, once again capitalising on the carer's presence with the person they care for to monitor the carer's health and wellbeing.

Such initiatives should be given due consideration given that the NSW Carers Strategy commits to improving the health and wellbeing of carers by "finding ways for carers to access services when they are accompanying the people they care for" (p.15).<sup>37</sup> There are also potential savings to be realised from this kind of holistic healthcare. Identifying and treating physical and mental health conditions are likely to improve carer wellbeing overall and assist carers to sustain their caring role, a factor identified in preventing the relinquishment of care recipients in health care and other facilities.<sup>38</sup>

Furthermore, preventative healthcare can reduce the likelihood of chronic conditions developing and associated complications which require extensive medical intervention or hospitalisation. Improved health and wellbeing of carers may also enable them to remain in paid work for longer.

**8. Carers NSW recommends that NSW Health provide dedicated nurses to conduct carer health assessments when carers accompany the person they care for in hospital or in primary and community health settings.**

### **3. SUPPORTING MENTAL HEALTH CARERS**

Carers NSW welcomes the 2015 changes to the NSW *Mental Health Act 2007* (the Act) that strengthen the rights of carers "to be kept informed, to be involved and to have information provided by them considered".<sup>39</sup> However, the impact of these changes has been limited by a lack of awareness among carers and health professionals.

Carers NSW is also concerned that the positive shift toward carer inclusion in the amended Act is being accompanied by a national step backwards in the provision of dedicated support to mental health carers. With people with psychosocial disability becoming eligible for the NDIS, and programs such as Mental Health Respite: Carer Support being in scope for the NDIS, opportunities for mental health carers to be supported in their own right are decreasing. We urge the NSW Government to maintain its innovative, targeted support and inclusion of carers in the mental health system.

### 3.1 Raising awareness of carers' rights

The recently amended Act includes a number of key changes affecting carers. Clinicians are now required to seek out and consider the views of carers and family members, in addition to other stakeholders, when making decisions about involuntary treatment and discharge. Carers are also entitled to have the person they are caring for admitted to a mental health facility and be provided with information about their medication.<sup>40</sup>

Clinicians must now notify carers when a consumer is detained, absent, discharged, readmitted as a voluntary patient or transferred between facilities. This also applies to the consideration of community treatment orders, electro convulsive therapy and special medical procedures. When there is evidence to suggest that a consumer has excluded a carer due to temporary lack of capacity, and that this exclusion would increase risks to the consumer or carer, this request may be put on hold.<sup>41</sup>

The amended Act also introduces two new categories of carer: designated carers and principal care providers. The former are nominated by the consumer as having a close personal relationship with them and being interested in their welfare. The latter are the persons primarily responsible for providing day to day support.<sup>42</sup>

Between 2014 and 2016, Mental Health Carers NSW (formerly Arafmi NSW) conducted a survey of 36 mental health carers living in NSW in order to determine the level of awareness about the changes to the Act and their implications. The findings indicated that less than one third of respondents had been advised of the changes. Given that one in five carers who were aware of the changes felt their experience of inclusion had improved as a result, there is an urgent need to improve awareness among carers and health professionals.<sup>43</sup>

Carers NSW understands that policy directives and training are being developed to help Local Health District staff implement the changes to the Act across NSW. However, Carers NSW is concerned that many carers are likely to remain unaware of the changes. We believe that comprehensive, targeted information and education will be required to bring carers up to date. This should be delivered statewide and in a range of formats, including face-to-face to ensure accessibility and equity for diverse groups of carers.

**9. Carers NSW recommends that NSW Health fund a statewide education and awareness campaign to improve understanding of amendments to the NSW *Mental Health Act 2007* among carers and health professionals.**

### 3.2 Maintaining carer support

The NSW Government has funded the Family and Carer Mental Health Program since 2005, acknowledging the need to support mental health carers and involve them in the care of their loved ones. The program is delivered by a range of NGOs and local area health services across NSW and provides:

- support and training for mental health workers to include carers in the service system and respond to their diverse needs
- education and training for carers to build coping skills and resilience
- individual support and advocacy for carers
- infrastructure support for carer peer support groups
- assistance in accessing generic carer supports<sup>44</sup>

Anecdotally, the individual support, groups and training delivered by the program are well subscribed, effective and highly valued by carers. Limited research has also indicated that training within the program facilitates peer-led learning and information sharing, validation of carers as 'experts', and timely referral to other support services.<sup>45</sup> However further evaluative data is required to demonstrate the success of this program in supporting carers.

The general dearth of reliable data, nationally and internationally, on the effectiveness of various carer support types was acknowledged by the discussion paper regarding the Australian Government's proposed Integrated Carer Support Service released for comment in May 2016.<sup>46</sup> The timing for capturing the effectiveness of carer-specific support programs is critical, as disability, mental health and ageing supports are rapidly transferring to an exclusive focus on the person with care needs, at the cost of adequate carer support.<sup>47</sup>

Formal evaluation of programs such as this will ensure that NSW remains a leader in carer inclusion and support nationally. A lack of data risks an undervaluing of carer specific support that is becoming evident in ongoing national reforms. However, Carers NSW also wishes to caution against the trend towards linking carer support funding to care recipient outcomes, as has previously been an issue in the program.<sup>48</sup> Evaluation should focus on outcomes for carers, including self-reported outcomes.

Furthermore, Carers NSW understands that, at the time of writing, funding for the program will be due for renewal at the beginning of the 2017-18 financial year. As one of the only NSW Government funded carer support programs that is not in scope for the NDIS, it is critical that funding for this program continues. Indeed, the program provides many examples of best practice in carer support that should be considered for expansion beyond the mental health sphere. Carers NSW understands that the program could also benefit from a funding increase to expand its reach.<sup>49</sup>

**10. Carers NSW recommends that NSW Health fund an evaluation of the Family and Carer Mental Health program and increase the funding allocated to the program in 2017-18.**

## 4. TRANSITION TO THE NDIS

The commencement of the 2017-18 financial year will coincide with the second year of full rollout for the National Disability Insurance Scheme (NDIS) in NSW, a transformational reform affecting hundreds of thousands of carers of people with disability. The gradual devolution of the state disability sector will also transform the carer support landscape, increasing the urgency of national reform.

During this period of considerable change, it is important that FACS monitor the impacts of transition on carers to ensure no carer is worse off and provide adequate information and support to help carers navigate the new system.

### 4.1 Accurate, timely information

Carers NSW has been advocating on behalf of carers for accurate, up to date information on the NDIS since the beginning of the trial phase in 2013.<sup>50</sup> Carers and service providers repeatedly report that the national NDIS website [www.ndis.gov.au](http://www.ndis.gov.au) and 1800 number are difficult to navigate. Much of the featured information remains limited in usefulness, out of date or full of jargon.

Carers NSW was very pleased to be engaged by the FACS NDIS Communications team in 2015 around the information needs of carers as part of its comprehensive stakeholder consultation, which is strongly reflected in the simplicity and accessibility of its own NDIS website, [www.ndis.nsw.gov.au](http://www.ndis.nsw.gov.au).

*Hong has heard that certain items essential to his son Eugene's care will not be covered by the NDIS. However he is frustrated by how difficult it is to access information on this. He feels that the NDIA phone line "just reads paragraphs" to him and doesn't adequately respond to his situation.*

The layout of the NSW website is easy to follow, the resources are available in multiple formats and translations, the topics are simple to understand and the language is straightforward. We also congratulate FACS on their Aboriginal specific fact sheets, especially the one on carers. However, we urge FACS to include an equivalent of this valuable resource for non-Aboriginal carers.

*Elaine cares for her adult son Oscar. She has attended a number of sessions about preparing for the NDIS, but often feels her questions go unanswered.*

Another limitation of the NSW website at the time of writing is that it has a very similar URL to the national site, and is not clearly advertised by the National Disability Insurance Agency (NDIA). This has caused confusion for carers and stakeholders, leading many to miss out on the superior NSW resources. A lack of promotion of the NSW website has aggravated this.

The major changes occurring with the commencement of full rollout in July 2016 and the introduction of the My First Plan approach were, from our perspective, not well communicated, leading to further confusion. Such changes could be more immediately highlighted on this website, and through other channels, in future.

Furthermore, Carers NSW believes that the NSW website should be linked to both a contact phone number and a regular e-newsletter, in order to enable people with disability, their families and carers, as well as stakeholders, to stay up to date with changes and additions to the website, and follow up the information with specific questions.

**11. Carers NSW recommends that the NSW Department of Family and Community Services fund a contact phone number and regular e-newsletter to accompany its NSW NDIS website.**

#### 4.2 Maintaining a provider of last resort

The NSW Government has historically been the provider of last resort for people with disability. This safety net is critical for people with disability who have complex needs and/or behaviours or concern, and their families and carers, who may otherwise be rejected by service providers due to the costs and risks associated with supporting them.

The transfer of ADHC services to the non-government sector and the introduction of a market-based disability support system under the NDIS put this group at risk. With no mandate to accept complex cases, it is likely that for-profits will consider them unprofitable, and not-for-profits unaffordable or too high risk. Even though NDIS funding is more generous in such cases to account for the extra costs associated with complex needs, Carers NSW believes that a provider of last resort must remain, whether it continues to be the NSW Government or the responsibility is delegated by FACS to another provider.

If the potential for certain people with disability to be turned away by service providers is not addressed, family and friend carers will inevitably be forced to fill the gap, often unsustainably. Providing intensive care at personal risk can have immense costs for carers, especially ageing carers, both in terms of their health and wellbeing and their social and economic participation.

*Diana's son Jeremy requires a specially designed bed due to behaviours of concern that are associated with his disability. This was never a problem when Jeremy was being supported by Ageing, Disability and Home Care (ADHC). However, after transitioning to the NDIS, use of the bed was rejected three times by restrictive practice panels, even though his need is well documented. For over 12 months his family were turned away by respite providers as they would not accept the bed. The family were also unable to access support through Commonwealth Respite and Carelink Centres due to Jeremy having an NDIS plan. After 12 months with no respite, the family is at breaking point.*

**12. Carers NSW recommends that the NSW Department of Family and Community Services maintain or delegate the status of provider of last resort.**

### 4.3 Taking responsibility for accessible public transport

Under the NDIS, disability service providers will no longer receive block funding to cover client transport. Participants will be expected to cover ‘reasonable and necessary’ transport costs with funding from their NDIS plan. We are also pleased to note that NDIS participants in NSW will remain eligible for the NSW Taxi Transport Subsidy Scheme (TTSS).<sup>51</sup>

The NDIS Operational Guidelines stipulate that the NDIS will be responsible for providing transport related aids and equipment or travel training to enable a person to travel independently using public transport. However, making public transport options available, accessible or affordable to participants clearly remains the responsibility of the NSW Government, as agreed in its Bilateral Agreement with the Commonwealth.<sup>52</sup>

However, anecdotal evidence suggests that ongoing deficits in the availability, accessibility and affordability of public transport, especially in rural and regional areas, are preventing many participants from engaging with their communities and realising their goals.<sup>53</sup>

When adequate public transport is not available and independent transport not an option, a person with disability is invariably dependent on a family member or friend to either accompany them when using public transport, or transport them personally using their own private vehicle. However, providing support with transport may disadvantage carers when it comes to obtaining or maintaining employment, and/or fulfilling other life responsibilities.

Carers NSW believes that carers should not be expected to provide any more transport support than what friends and family members of people without disability would be expected to provide. This expectation partly hinges on adequate NDIS funds to cover transport, however public transport vehicles and routes that optimise inclusion and independence for people with disability will also play a key role. Innovative solutions such as the flexible route service project Carers NSW has heard will be piloted in NSW are a great start.<sup>54</sup>

*“My son has Down Syndrome and transport is our main problem for him. NDIS just cannot sufficiently provide it for him. It’s really stressful for my wife, having to get up early to take him wherever he needs to be. They have three buses to catch, therefore he and my wife need to get up at 5:30 AM, to get him dressed, have breakfast and then on the bus by 7 AM. They tried travel training which didn’t work...He used to get support through his service provider 4 days a week, but now he only gets support on Tuesdays for gym. The other three days were computer skills, art and living skills. Because he hasn’t been able to get there, he’s lost his interest in those things.” – Transport forum participant<sup>49</sup>*

**13. Carers NSW recommends that Transport for NSW prioritise increasing the frequency and variety of accessible public transport options in rural and regional areas.**

State funded community transport has also been an important option for people with disability and their carers, with both groups being able to access this service at a low cost under the previous system. The shift to individualised support places this option in jeopardy,

as it appears that community transport providers are receiving reduced funding overall, making it difficult for them to cover fleet purchase and upkeep, and to adequately subsidise fares. Furthermore, the NDIS does not fund services for carers, so carers' out of pocket transport costs may increase.

**14. Carers NSW recommends that Transport for NSW and the NSW Department of Family and Community Services ensure affordable community transport options remain for people with disability and their carers, regardless of their NDIS eligibility.**

Carers out of pocket transport costs may further increase if the rollout of the NDIS in NSW places eligibility for the Companion Card in jeopardy. Carers NSW has been advised that some NDIS participants may be ineligible for a Companion Card<sup>55</sup>, however it is unclear to Carers NSW why NDIS participants should be excluded, especially as unpaid carers are not direct beneficiaries of NDIS plans. It also appears that this is not the case in other states.

**15. Carers NSW recommends that the NSW Government continue to fund Companion Card eligibility for NDIS participants and quarantine the program from NDIS transition.**

#### 4.4 Navigating sector reforms

2017-18 will mark the final year of full rollout phase for the NDIS in NSW. An unprecedented number of participants will come on board during this period, with large numbers also awaiting their first plan review.<sup>56</sup> The stress and confusion experienced by carers thus far<sup>57</sup> is therefore unlikely to abate during this 'surge' phase.

In addition to the improved information discussed in Section 4.1, Carers NSW believes some form of individual advocacy or case management is warranted during this period of extensive change. Disability advocacy services exist to help participants through the transition, but carers' individual rights and experiences are not a focus.

Carers NSW has long advocated for an individual carer advocacy program<sup>58</sup>, as no such program exists on a national level, and the majority of carer program funding accessed by carers in NSW does not explicitly include individual advocacy. And yet, carer advocacy has been identified as a major need.<sup>59</sup>

Some NSW Government funded carer-specific programs have included an advocacy component, for example, the Older Parent Carer Support Coordination Program, the My Plan My Choice pilot program and the Family and Carer Mental Health Program. However, two out of three of these examples are soon transitioning into the NDIS and they only support relatively small, defined groups of carers. Carers NSW believes an individual advocacy program to help carers in the transition period would be highly beneficial and could follow the delivery models of existing programs.

**16. Carers NSW recommends that the NSW Department of Family and Community Services fund an individual advocacy program available to all carers of people with disability throughout the NDIS transition period.**

## CONCLUSION

Carers NSW would like to thank the NSW Government for its ongoing commitment to carers and for this opportunity to contribute to the future direction of our state. Our submission has highlighted four key areas in which the needs of carers ought to be prioritised, and we urge the NSW Government to consider our recommendations as it prepares to deliver the 2017-18 Budget.

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

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