



## **Keeping carers at the centre**

**Carers NSW Pre-Budget Submission 2020-21**

## ABOUT CARERS NSW

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

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

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

<https://twitter.com/CarersNSW>

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## ABOUT CARERS

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

Across NSW, there are approximately 904,400 carers,<sup>1</sup> and to replace the care they provide the NSW Government would have to spend more than \$17 billion each year.<sup>2</sup> 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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<sup>1</sup> Australian Bureau of Statistics (2017) *Disability, Ageing and Carers, Australia: Summary of findings, 2015*, New South Wales Tables, Canberra.

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

## INTRODUCTION

In the past twelve months, much has changed for carers in New South Wales (NSW). In the second half of 2018, 14 innovative, carer-focused projects funded by the NSW Department of Communities and Justice (DCJ) commenced under the Carer Investment Program (CIP). These projects represent a \$1.86 million per annum investment by the NSW Government over three years in supporting carers. Carers NSW is pleased to be delivering three of these projects statewide.

In November 2018, the national grant opportunity to deliver in-person carer supports as a Regional Delivery Partner (RDP) under the new Integrated Carer Support Service (ICSS) opened, with many organisations in the carer support sector in NSW preparing bids. In July 2019, the digital service components of the ICSS were launched via the national Carer Gateway, and in August 2019, the results of the RDP tender were announced.

Carers NSW is pleased to have been selected as the preferred RDP provider for the NSW 4 service delivery area, covering the Central Coast, Hunter New England and North Coast regions of NSW, and looks forward to working with carers and the sector in implementing this important reform. Carers NSW, our subcontracted partner organisations and the three other lead organisations in NSW and their consortia will roll out six in-person service types from April 2020, replacing the current Commonwealth funded carer support service system.

2019 also marked the beginning of the co-design of the next NSW Carers Strategy, with carers from across NSW participating in workshops and consultations. Carers NSW commends DCJ for its commitment to genuine co-design with carers. Carers NSW looks forward to continuing to work with the NSW Government on the design and implementation of the new Strategy into the next financial year and beyond.

The 2020-21 financial year will bring continued change and celebration for carers in NSW. The ICSS will be fully up and running, and the NSW Carers Strategy 2020-2030 will be finalised and launched, bolstering the State's commitment and direction in supporting carers and providing new opportunities for collaboration and innovation.

2020 also marks the ten year anniversary of the NSW *Carers (Recognition) Act 2010*, a ground breaking piece of legislation for NSW that has led to increased awareness of the needs and experiences of carers in the public sector and broader community. As well as watching the sector changes closely, 2020-30 will be a time for the NSW Government and carers in NSW to celebrate how far we have come in recognising and supporting carers.

Drawing on extensive consultation with carers and other key stakeholders, this Pre Budget Submission highlights some key areas in which Carers NSW has identified NSW Government spending will be required in this period of great transition in order to keep carers at the centre:



## 1. CONTINUE PROMOTING CARER RECOGNITION

Since the enactment of the NSW *Carers (Recognition) Act 2010* (the Act) Carers NSW has included questions in our biennial Carers NSW Carer Survey to gauge the extent to which carers are experiencing an increase in recognition. Recognition has remained low among respondents since the 2010 survey,<sup>1</sup> with 43% of respondents in 2018 still disagreeing that their caring role was recognised and valued by their community.

In the Carers NSW 2018 Carer Survey, Carers NSW also introduced questions regarding the extent to which carers were involved in decision making and asked about their own needs in a range of service settings. It was troubling but not surprising to Carers NSW to find that while carers were commonly included to some extent in the provision of services to the recipients of their care, they were much less frequently recognised as having their own needs<sup>2</sup> (see Figure 1).

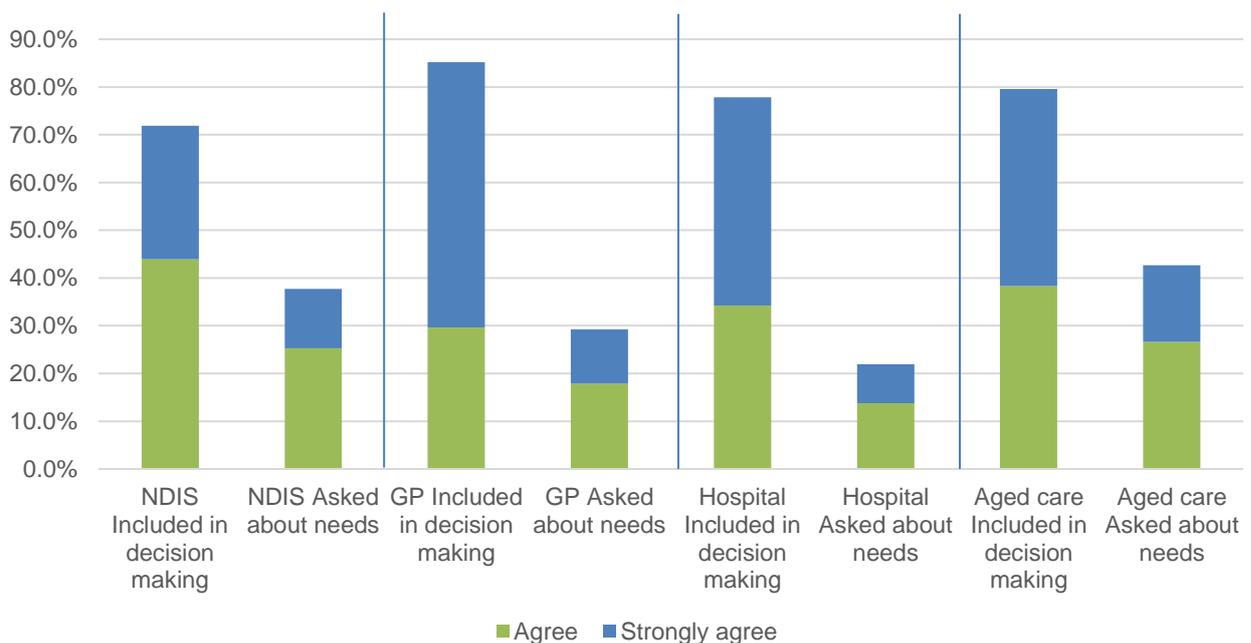
*“Carers are invisible to the community. It is something community doesn’t want to talk about.”*

*“As my daughter has a hidden disability, many people do not realise the amount of time and effort needed to assist her.”*

*“I am tired of people saying how sorry they are about my situation...Actions not words are helpful.”*

- Carers NSW 2018 Carer Survey respondents

Figure 1: Carer inclusion in service settings



Carers NSW has been working with the NSW Department of Communities and Justice (DCJ, formerly the NSW Department of Family and Community Services, or FACS) since 2010 to raise awareness of and increase compliance with the Act within the NSW public sector. Carers NSW commends DCJ’s efforts in promoting the legislation and NSW Carers Charter to carers, the public sector and communities but has also found that many of the NSW Government departments and agencies with whom we interact are not aware of the Act and/or that it holds obligations for their organisation.

Carers NSW is pleased that carer recognition is an ongoing priority for DCJ and looks forward to the opportunity the ten-year anniversary of the Act and the launch of the new NSW Carers Strategy present for raising further awareness of the needs and experiences of carers in NSW. This section explores some concrete recommendations for how the NSW Government can capitalise on these opportunities in order to improve carer recognition in NSW.

## Recommendations

- Maintain and expand targeted carer investment (p. 5)
- Maintain a carer-inclusive approach to preventing the abuse of vulnerable adults (pp. 5-6)
- Enhance carer recognition in the public sector and community (pp. 6-7)

### Maintain and expand targeted carer investment

Carers NSW and a range of other organisations in NSW are currently the beneficiaries of CIP funding for innovative, carer-focused projects complementing the NSW Carers Strategy. The 14 projects funded by the CIP reflect a welcome emphasis on carer employment, peer support, health and wellbeing and on young carers and Aboriginal and Torres Strait Islander carers. Investment in targeted projects addressing these areas of need is critical and Carers NSW commends DCJ for providing ongoing funding to such projects.

*“Carers value each other as we gain love, friendship and support for each other; as for the broader community, it goes unrecognised.”*

- Carers NSW 2018 Carer Survey respondent

Noting that these projects are funded for a maximum period of three years (to June 2021), Carers NSW recommends that as part of the development of the new, ten-year Strategy further opportunity for funding carer projects be prioritised. The in-depth consultations taking place within the Strategy co-design will provide a useful evidence base for determining investment opportunities, in conjunction with the results of the Carers NSW 2018 Carer Survey, referred to throughout this submission. During the 2020-21 period, funding should be allocated to ensure that successful projects be continued and/or expanded, ensuring a smooth transition and preventing funding uncertainty for the organisations, staff and carers involved in these projects.

2020-21 will also be a critical time for allocating ongoing funding to carer-focused projects in NSW as by early 2021, all six in-person ICSS support types will have been rolled out, with carer coaching the last to be implemented from February 2021. All large scale sector reforms result in unintended service gaps, and the 2020-21 period will be a critical period for determining what the emerging gaps are in NSW. Carers NSW has some early indication of what these might be, but as noted in Section 2, we encourage the NSW Government to invest in ongoing monitoring of the reforms and to commit to addressing gaps arising that disadvantage carers in NSW, especially diverse carers that DCJ has identified as being particularly at risk of disadvantage, such as LGBTIQ+ carers, Aboriginal and Torres Strait Islander Carers, young carers, carers of people living in social housing and carers of people with drug or alcohol dependency.

### Maintain a carer-inclusive approach to preventing the abuse of vulnerable adults

Carers NSW welcomes the appointment of Robert Fitzgerald as the NSW Ageing and Disability Commissioner and supports the introduction of an accountability mechanism for older people and people with disability experiencing, or at risk of experiencing, abuse, neglect and exploitation within

their home or community. We were pleased to have Mr Fitzgerald speak at our recent Carers NSW Conference 2019 on the establishment of the Commissioner and the importance of a nuanced and inclusive approach to working with carers in this environment.

Carers NSW also commends DCJ and now the Commissioner and his team for being proactive in engaging Carers NSW to inform the design and implementation of the Commissioner's role. In response to concerns expressed by Carers NSW in previous years with regard to the framing of carers in relation to elder abuse, we have been pleased to see greater recognition of the commonly complex family dynamics in which abuse takes place and the need for a preventative and supportive approach when working with families experiencing stress as a result of caring responsibilities. We look forward to continuing to provide feedback on the Commissioner's jurisdiction and initiatives into the future.

Carers NSW was concerned that mandatory reporting was raised in the debate around the *NSW Ageing and Disability Commissioner Bill 2019* and cautioned that further consultation and consideration would be required in order to make an informed decision on this recommendation. We also welcome the inquiry into disability advocacy, as Carers NSW has long advocated for these organisations to continue to receive funding from the NSW Government. The latter point is explored further in Section 2.

Carers NSW also believes that further exploration of the risk factors and preventative measures associated with the abuse of vulnerable adults should be a key action pursued by the Commissioner, in order to establish, among other matters, the prevalence of abuse perpetrated by carers (defined as per the *NSW Carers Recognition Act 2010*) as compared to other parties, the extent to which carer stress and support affect the likelihood of abuse, the extent to which carers who perpetrate abuse are aware that the action constitutes abuse, and the frequency with which carers themselves are subject to abuse within home and community settings. This kind of research is sensitive and costly but critical to contributing to a nuanced and informed understanding of the abuse of vulnerable adults.

### Enhance carer recognition in the public sector and community

The introduction of the new Strategy and the ten-year anniversary of the Act and Charter present a timely opportunity for investment in a state-wide awareness campaign about carers, including targeted awareness within government department and agencies who have obligations under the Act. A key cause of confusion within government and the community is the legislated definition of the term carer. This will become increasingly important as the ICSS rolls out as the definition is the key determinant of eligibility for carer support.

Across NSW Government departments and agencies, including DCJ, and commonly within the community, the term 'carer' is used not only to refer to carers as the Act defines them, but also to foster carers, kinship carers, paid care workers and volunteers. While this is a

*"Many of us suffer violence and injuries, assaults and abuse from the people we care for, nobody is counting, no solution will be found until you quantify it. Start asking the question, we deserve to live safely and with support."*

*"Someone who is immobile and can't speak out her needs like mum is totally exposed...Where I speak out for mum...the nursing home accused me of asking for 'intensive care' and making me feel bad for simply being caring and being an advocate for mum. If I don't visit mum, she will simply get neglected."*

- Carers NSW 2018 Carer Survey respondents

*"Awareness & community education enlighten peoples' mind in the community that a caring role is a noble profession and that community really appreciate it."*

- Carers NSW 2018 Carer Survey respondent

national problem, there is much the NSW Government could do to improve this by being more consistent and accurate in its own use of these terms. The further clarification to the Act's definition of carer in the 2016 review provided a more straightforward reference point for explaining the difference between these different types of 'carers', however there is still little awareness within the public sector and community.

Carers NSW therefore recommends that DCJ invest in simultaneous awareness campaigns within the NSW public sector and broader community around the definition of 'carer' as part of its Strategy implementation to address these common misconceptions. These awareness campaigns could also tie into the work Carers NSW is conducting in partnership with DCJ and various complaints sector representatives regarding awareness of carers' rights and complaints pathways.

## 2. ADDRESS EMERGING SERVICE GAPS

The aged care, disability, mental health and carer support sectors in NSW have each been undergoing major reforms in recent years, with the increasing nationalisation of previously state or jointly funded services. Carers NSW wishes to reiterate that due to restrictive eligibility criteria, funding changes and teething problems associated with new systems, carers continue to experience significant gaps in NSW.

As emphasised in previous Pre-Budget Submissions, Carers NSW is concerned that following the closure of Ageing, Disability and Home Care (ADHC) in 2018, residual funding for disability services and capacity building support has been very limited, far from addressing the needs of all those in NSW who are ineligible for the NDIS or not receiving adequate support in their NDIS plan. In many cases, an inability to access adequate services results in increased strain on carers who are required to provide additional care without support or assistance. While the aged care reforms are more progressed, some gaps also remain for over 65s and their carers. Persistent gaps across both sectors include equipment, transport, planned replacement care and thin markets in regional and remote areas.

In addition to gaps in services for care recipients, a number of pre-reform carer support types have been lost and are yet to be replicated. Carers NSW welcomes the introduction of the ICSS from April 2020 and is pleased to be part of the implementation of the new system in NSW. The ICSS model reflects the Commonwealth's recognition that a national system dedicated to carer support is needed alongside the NDIS and My Aged Care in order for a carer focus to be retained. However, while holistic in many regards, the ICSS model does not replace all forms of carer support offered currently or pre-transition. We wish to emphasise that some service gaps will remain, and potentially emerge, following ICSS implementation, necessitating an ongoing role for the NSW Government in the provision of carer support.

For example, the ICSS does not provide much in the way of planned respite, does not fund respite infrastructure and offers limited assistance for carers experiencing financial hardship and/or seeking to increase their engagement in the workforce. Case management and advocacy – two service types that are rapidly disappearing from the disability sector in favour of shorter term capacity building focused interventions – are also out of scope. While peer support is included in the model, practical and financial support for existing carer support groups and facilitators appear to be limited, with carer education and training restricted to online modules or structured delivery within peer support groups. Finally, support types popular among carers such as tutoring, recreational activities and retreats have no clear place in the new system.

Carers NSW looks forward to working closely with both the NSW and Commonwealth governments in monitoring the implementation of the ICSS and identifying arising challenges and opportunities.

Noting the significant role the NSW Government has played in advocating for changes to the disability/health interface through the Disability Reform Council, we urge a similar approach to be taken with regard to the implementation of the ICSS in NSW. The recent inclusion of disability-related health supports, including dysphagia, continence, diabetes managements and respiratory supports, under the NDIS<sup>3</sup> indicates the influence the NSW Government can have in ensuring equitable service delivery through Commonwealth led reforms.

This section explores some concrete recommendations regarding known service gaps for carers that the NSW Government can address within the 2020-21 Budget period:

## Recommendations

- Make essential equipment available to people unable to access it elsewhere (pp. 8-9)
- Improve mainstream service access for children with disability (pp. 9-10)
- Safeguard service users from market failure (p.10)
- Continue supporting NSW residents with service navigation (p. 11)
- Invest in continuity of support for carers at a time of transition (pp. 11-12)

### Make essential equipment available to people unable to access it elsewhere

Currently, people with disability, who are participants of the NDIS are ineligible for equipment funded by EnableNSW. Whilst they can utilise their NDIS funding to purchase items from Enable NSW, carers have reported a number of cases where NDIS funding for equipment has been delayed due to lengthy and complicated Assistive Technology or review processes. In these cases, carers report that NDIS participants have been unable to access adequate equipment that enables their carer to safely or effectively provide care, placing both the person with disability and their carer at risk.

Similarly, those who are ageing or frail and have been approved for a Home Care Package are also ineligible for EnableNSW funded equipment. Currently, as of 31 March 2019, there are 73,978 people who are approved and waiting for a HCP at their approved level who have not yet been offered an available HCP at a lower level as an interim measure.<sup>4</sup> For people who are ageing or frail, informal care is most commonly provided by spouses or partners, who are often ageing or frail themselves.<sup>5</sup> This means that additional strain is placed on carers, many of whom are ageing or frail, to provide care without the appropriate or adequate equipment to support them.

*“Our difficulty has been in interpreting what has been provided for and the lack of speed in getting equipment scripted and approved. Some of which is necessary to allow myself as a carer to have assistance in the house (e.g. hoists).”*

*Awaiting shower/commode chair and manual wheelchair which both have still not arrived despite plan commencing [two years prior]...Unable to get outside help to shower without equipment and in the meantime the child has grown and deteriorated in his mobility.”*

- Carers NSW 2018 Carer Survey respondents

Carers NSW recommends that the NSW Government widen the eligibility of EnableNSW to ensure that no person requiring assistive technology is unable to access the necessary equipment to enable their carer to provide safe and supportive care. Loans could be an interim measure for people awaiting funding allocation, however it should be noted that some individuals, in particular those with a Home Care Package, may simply not have enough funding to access the equipment they need as budgets are capped. Further, people with significant, permanent disability over the age of 65 and therefore ineligible for the NDIS may require disability related equipment beyond the typical provision for those who are frail aged.

### Improve mainstream service access for children with disability

Carers NSW commends the NSW Government for its considerable investment in expanding access to transport and child care services via a range of initiatives in the NSW State Budget 2019-20.<sup>6</sup> However, additional investment in these areas is needed to ensure that they are inclusive of children with disability and their carers.

Carers have reported that the NDIS will not fund appropriate before or after school transport for their children in NSW, as the mainstream services that exist are often overly prescriptive and do not meet their needs. Carers have reported to Carers NSW that the NSW Government funded Assisted School Travel Program (ASTP)<sup>7</sup> only transports children to and from their home, with other locations (such as after school care) not being an option. This restricts access to the service for children who are accessing child care services outside of schools hours, and which may enable carers to attend to other responsibilities such as paid work.

In line with the NSW Government's commitment to increasing the inclusion of people with disability in education and community settings, Carers NSW recommends increased investment in the ASTP to enable greater flexibility, including the provision to transport young persons with disability to available mainstream or specialised after school services. Ongoing funding to support increasing inclusiveness of public transport and child care services may supplement this, providing a greater range of mainstream options that may be able to meet carer needs over time.

Jo's\* son Neil\* is an NDIS participant. Jo works part time, requiring Neil to attend after school care two days per week. However, Neil requires supported transport to his after school care provider due to his disability. Jo has been advised that under the ASTP, her son can only be transported to their family home. However, the NDIS has also declined to fund transport from Neil's school to the provider as there are available mainstream supports. Jo is worried that she will have to cease employment if she cannot find appropriate transport.

\*Names changed

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

Although public education services are required to be accessible and inclusive under the NSW Disability Inclusion Act 2014 and this recent funding commitment emphasises that all children will access BASC programs, some carers have reported to Carers NSW that they have tried to use mainstream services, but have been told by Government BASC services that they cannot accommodate their child due to their level of need. Many simply do not have the accessible spaces,

equipment and staffing ratios required to cater to the needs of children with significant, permanent disability.

In instances where children with disability are unable to participate in BASC programs, carers are often required to provide support and care themselves, which may impact on their responsibilities outside the caring role, including their participation in paid employment. This can have significant implications for family finances and for carers' socio-economic participation and associated wellbeing.

Carers NSW recommends that the NSW Government ensure that its current initiatives to expand access to child care, take the needs of children with disability and their carers into account, funding specialised training and additional staff to enable the inclusion of all children in out of school hours care.

### Safeguard service users from market failure

The transition to the NDIS in NSW included the transfer of specialist disability and community care services from NSW Ageing, Disability and Home Care (ADHC) to non-government organisations, including Australian Unity. Carers have reported to Carers NSW that in some regional and remote communities, Australian Unity is the only provider – or one of few – that can provide certain NDIS services. However, unlike ADHC, as an open market participant, Australian Unity has no formal obligation to continue to provide financially unsustainable services as the provider of last resort, even if no or few other providers are available. Australian Unity's withdrawal in May 2019 from the provision of NDIS services in some areas threatens to reduce, or indeed, remove choice and control from people with disability, their families and carers.<sup>8</sup>

The NDIA has indicated that services for participants may be directly commissioned for a short period of time as provider of last resort, however it is unclear how such an arrangement would be facilitated in the NSW context.<sup>9</sup> The NSW Government must provide information in regards to these provisions in light of the significant changes occurring for Australian Unity clients, in order to reduce the uncertainty and stress many participants, their families and carers are experiencing.

Additionally, in the aged care context, many providers are reporting that they are running at a loss, especially those in regional and remote areas that face additional challenges to providing services.<sup>10</sup> Whilst aged care falls squarely within the Commonwealth's jurisdiction, the NSW Government has a responsibility to engage on the matter to ensure the ongoing availability of services and infrastructure to safeguard older people in NSW and their carers.

The NSW Government should ensure that bilateral agreements are in place in both the aged care and disability sector to ensure that no individual is in the position of having no available service provider. Additionally, the NSW government should invest in residual community care services in NSW to provide a robust safety net in situations of market failure.

Bob\*'s family has received in home services for their daughter with a disability from Australian Unity (previously Home Care) for over 40 years, however they have been notified that Australian Unity services will be ceased over the next 12 months.

Bob reported that he and his wife (both over 60) are already providing two of the services funded by NDIS as they are currently unstaffed as they have been unable to source suitable care workers for the times required.

\*Name changed

## Continue supporting NSW residents with service navigation

While many people with disability in NSW are able to access supports through the NDIS, a large proportion will never be eligible. Ability Links NSW has been meeting some of the needs of these individuals, connecting people with disability, their family and carers to inclusive and mainstream activities in the community. The Ernst & Young Ability Links NSW Social Impact Evaluation calculated a benefits of \$3.60 for every dollar cost delivering Ability Links NSW. They estimated that the program resulted in over \$11 million of government cost savings in 2016-17.<sup>11</sup> Similarly, Urbis approximated that the benefits for 2015-16 were approximately \$47.8 million.<sup>12</sup>

Carers NSW commends the NSW Government on its commitment to the ongoing joint funding with the NDIA of Ability Links NSW for 2019-20.<sup>13</sup> However, it has been noted that some Ability Links programs have now ceased, with the roles transitioning to NDIS Local Area Coordinators (LACs) under the Information, Linkages and Capacity Building (ILC) component of the NDIS. This cessation of Ability Links NSW services well before the implied June 2020 date is in complete contradiction of the 2019-20 State Budget commitment to continue funding the program.

The Carers NSW 2018 Carer Survey found that over two thirds of respondents caring for an NDIS participant and almost half of respondents caring for a person under the age of 65 who was not accessing the NDIS had experienced an increase in time spent organising supports for their care recipient since the roll-out of NDIS in 2016.<sup>14</sup> Many carers have reported to Carers NSW that the additional strain associated with navigating disability reforms has placed immense strain on their health and wellbeing, and in some cases to such an extent that it has disrupted caring arrangements.

Many carers inform us that they rely on specialist disability peak and advocacy organisations across NSW for reliable information about the condition of the person they care for and support in accessing services. The impending cessation of this funding scheduled for 30 June 2020 is causing many carers great distress and is compromising the viability of many disability advocacy organisations. The resulting uncertainty places a wealth of specialist knowledge and networks at risk.

As in previous Carers NSW pre-budget submissions, Carers NSW urges the NSW Government to respond to the requests of disability advocacy organisations to continue funding into the 2020-21 financial year and beyond. ILC and the National Disability Advocacy Program (NDAP) only offer limited support, and Carers NSW believes that the NSW Government should retain responsibility for supporting its residents to interact with state funded service systems such as transport, social housing and health, where, as disability advocacy organisation inform us, most of their work is done.

## Invest in continuity of support for carers at a time of transition

As a result of sector reforms, the majority of State and Commonwealth carer support funding has either already transitioned, or will soon transition, to the NDIS or ICSS.<sup>15</sup> By the end of the 2019-20 financial year these transitions are intended to be complete. Many of the outcomes achieved under prior carer support programs are replicated within these two systems, and new types of support will be offered.<sup>16</sup>

However, the NDIS and ICSS assume the ongoing existence of State and Territory services to which carers and people with disability can be referred. Additional, ongoing funding from the NSW

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

\*Names changed

Government will be required to maintain the necessary infrastructure to support the implementation of the NDIS and ICSS and to act as a safety net for carers whose needs are not being met under these systems. The 2020-21 financial year will be a key period for the NSW Government to closely monitor these emerging gaps and respond with strategic, long term solutions. Key gaps Carers NSW has identified where NSW Government investment would be beneficial are detailed below.

Whilst it is intended that under the ICSS there will be some provisions for carer peer support, the ICSS does not provide funding for carer support groups. Carer support groups previously received funding from the NSW Government under the *together* Program, however this funding ceased in 2018 with the closure of ADHC. Carers NSW continues to connect and support carer support groups across NSW through the CIP funded Carer Peer Connect program, however this does not provide financial support to independent carer support groups and most are dependent on either voluntary support group facilitators and facilities, which do not appear to be within scope of the ICSS peer support model, or paid positions within organisations who will be losing funding as a result of sector reforms.

The Victorian State Government, in acknowledgement of the important role of in person carer support groups committed \$4 million of funding in 2019-20 in the form of grants to informal groups of carers or larger carer organisations to ensure the continuation of carer support groups in Victoria.<sup>17</sup> Carers NSW urges the NSW Government to consider expanding its commitment to peer support, already exhibited in the CIP funded Carer Peer Connect and Weavers projects, to include grants to keep groups in operation without further strain on carers.

The ICSS model includes a limited supply of packages of up to \$3,000 per year that can be used to purchase respite, among other supports, and provision of emergency respite to carers in crisis. The model relies upon other service systems to address other instances of planned respite. Carers NSW is concerned that in NSW both the physical infrastructure and service funding available is inadequate to meet the need, given that it is clear most carers do not receive adequate planned respite through the NDIS and aged care systems.<sup>18</sup> Respite facilities in particular have struggled to remain viable under individualised funding models.

The Victorian State Government, in acknowledgement of the ongoing carer support shortages, recently committed to a nearly \$50 million package for carers over four years, including funding for respite services in Victoria, expecting to provide an extra 100,000 hours of respite for 5,000 carers per year.<sup>19</sup> Carers NSW commends the NSW Government on its commitment to the funding of critical respite infrastructure in Queanbeyan in the 2019-20 State Budget for people with life-limiting illnesses and recommends the NSW Government consider mapping existing and at risk stock in NSW and providing grant based funding to maintain this critical infrastructure.

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

- Carers NSW 2018 Carer Survey respondent

Another Victorian initiative that could be considered in NSW is the introduction from July 2019 of half price public transport for carers with a Carer Card and Carers Myki. While the Carer Card concept has been explored in NSW on more than one occasion and not implemented, Carers NSW recommends that the development of the next Carers Strategy consider a similar measure.

Finally, given the ongoing need for State based support for carers, Carers NSW urges funding for local health district (LHD) carer programs, the Family and Carer Mental Health Program, the Carer Investment Program and Carers NSW peak and young carer funding to continue, as the support these programs provide is not being replicated elsewhere in the service system.

### 3. SUPPORT HIDDEN YOUNG CARERS

According to the 2015 Survey of Ageing, Disability and Carers, there are approximately 96,000 young carers in NSW who are aged 25 years and under.<sup>20</sup> Young carers provide a variety of practical, specialist and emotional assistance which often exceed community expectations of what a child or young person can and should be responsible for. The tasks undertaken by young carers can range from domestic duties such as meal preparation and cleaning, to personal care such as showering, to supervising siblings and providing emotional support.<sup>21</sup>

While young carers often gain important skills from their caring role as well as a sense of pride, satisfaction and a strong bond with the person they care for, young carers are more likely to experience a number of vulnerabilities when it comes to their own health and wellbeing, social participation, education and employment.

A young carer's capacity to complete education and participate in paid work is significantly affected by the intensity of their caring role, including the number of hours they care, the tasks they perform and their access to alternative support.<sup>22</sup> Results from the 2016 Carers NSW Carer Survey, for example indicated that the participation of young carers in paid employment was significantly affected by their caring role, with many indicating that they had stopped work or changed their work hours to accommodate caring responsibilities, while others were in a job below their skillset or were reluctant to take on work entirely.<sup>23</sup> More recent research has also indicated that certain types of caring roles are linked to lower school engagement and performance.<sup>24</sup> As a result, young carers, especially those with intensive caring roles, are at risk of long term disadvantage.<sup>25</sup>

The situation is further complicated in that many young carers do not identify as young carers, either because they or the people around them do not know what a young carer is, or because they are afraid of the implications of disclosing their family situation, which may lead to stigma, bullying or raise questions of child protection.<sup>26</sup> Failing to identify can prevent young carers from accessing support at school or university, in the workplace, in the community and within service systems.

Carers NSW commends the NSW Government for its continued support and recognition of young carers, particularly in the context of the NSW Carers Strategy 2014-19 (the Strategy) and NSW *Carers (Recognition) Act 2010* (the Act), and for its ongoing funding of young carer projects, including those delivered by Carers NSW. Carers NSW is also pleased that young carers have been prioritised for education and employment support at Commonwealth level through the Try, Test and Learn and Young Carer Bursary programs, and more recently with the announcement at the last Federal Budget of targeted support to be made available to young carers through the ICSS.

In spite of these initiatives, many young carers who do identify as carers continue to have limited support options, and many others are not aware of the support that they can access. This section addresses several key areas in which increased investment from the NSW Government would help more young carers identify and access needed support:

#### Recommendations

- Tailor school and vocational education policy to accommodate young carers (pp. 14-15)
- Fund targeted initiatives for young carers in regional and remote areas (pp. 15-16)
- Promote inclusive recreational activities to young carers (p. 16)

## Tailor school and vocational education policy to accommodate young carers

Carers NSW was pleased to see a number of initiatives announced in the 2019-20 State Budget focused on improving access to support for children and young people within school and vocational education, including hundreds of new school counsellor and student support officer places and tens of thousands of free traineeships for young job seekers.<sup>27</sup>

The additional 100 school counsellors and psychologists and 350 student support officers being appointed across NSW provide a key opportunity to both expand student support available to young carers in schools and increase the young carer awareness of the student support workforce. A recent Carers NSW project funded by the NSW Government's Youth Opportunities program, *Who Cares, Wins* engages with senior school students via a Q&A-style session featuring a young carer leader, facilitated by a school representative who is often a school counsellor. By sharing the experience of a young carer with their peer group this project has raised the profile of young carers in schools.

Of the 260 students reached by this project so far in NSW, 17 who had not previously identified as a young carer identified as a result of the session, and 57 realised they had a friend who was a young carer. Nearly all participants indicated that they better understood who young carers were following participation in the program. Targeted outreach within schools, in collaboration with staff 'champions' like school counsellors and with the support of young carers themselves, has the potential to identify many more young carers and connect them with support. Unfortunately, however, the impact of this project was limited by challenges gaining access to schools and the reticence of some young carers to share their experiences in their own schools.

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

- Young carer

Carers NSW recommends that the NSW Department of Education promote increased engagement among schools in carer identification and education and integrate young carer outreach and support into its mainstream initiatives supporting staff and students around mental health, health and wellbeing. Training and resources regarding young carers such as the Carers NSW Young Carer Toolkit should also be made mandatory among school counsellors and student support officers in order to raise awareness, increase engagement and reduce stigma. As a public service agency, the Department is obligated to reflect the NSW Carers Charter in its work, including the principles regarding timely support and referral, support to balance caring with education and enabling children and young people who are carers to reach their full potential.<sup>28</sup>

Furthermore, Carers NSW recommends that the NSW Department of Education consider funding the development of a resource for school counsellors on young carer identification in the school context, building on existing resources such as the *School Refusal – Every School Day Counts* resource, developed by South-Eastern Sydney Local Health District (SESLHD), which provides guidance on how to engage with students, including young carers, who may have difficulty in meeting school attendance requirements. While this resource does mention the possibility of care interrupting a student's education, a young carer specific resource would be more effective in building the capacity of school counsellors, teachers and other staff members, as caring roles can differ significantly based on the level of intensity of the caring role or the nature of the care provided, affecting each young carer differently, and recent research indicates that particular kinds of caring roles are simultaneously more likely to remain hidden and more likely to impact school engagement.<sup>29</sup>

Carers NSW also encourages the NSW Government to consider explicitly including young carers in the eligibility criteria for relevant youth focused vocational training initiatives such as the free

traineeships for young job seekers announced in 2019 and the Smart and Skilled program. Furthermore, quarantining a portion of these apprenticeships for young carers and working in collaboration with Commonwealth funded young carer employment support programs (such as the Carer Achievement Pathway project, delivered by Carers NSW and the Young Carer Bursary, managed by Carers Australia) would allow young carers to receive more holistic support, assisting them to overcome some of the many barriers they face to pursuing further education and employment.<sup>30</sup>

Another way in which existing policies and programs can be adapted to accommodate young carers is by ensuring the statewide mobile phone ban in primary schools announced in 2018 include flexibility and exemptions that can be applied where mobile phone access is required in connection with caring responsibilities. While remote supervision and monitoring by a child may not result in the best educational outcomes, in some families this is necessary, for example where a single parent requires physical or emotional support, or where a sibling requires accompaniment home from school due to a disability. Young carers commonly report feeling anxious or worried while away from the person they care for.<sup>31</sup> To alleviate this stress and anxiety, access to mobile phones means that young carers can be contacted in the event of an emergency or can contact the person they care for to check in with them at appropriate times throughout the day.<sup>32</sup>

Carers NSW supports policies which seek to enhance educational outcomes of students. However, it is imperative that flexibility and inclusion is in-built to support young carers in their caring role and reduce any associated anxiety resulting from the banning of mobile phones in schools. As well as flexibility, this policy also provides a potential opportunity for young carers to self-identify and be referred to support. If an exemption is implemented, a supportive approach should be taken in making this known and in ensuring that the disclosure of a caring role results in subsequent support from the school.

Finally, targeting school tutoring support for young carers that is currently provided by Commonwealth Respite and Carelink Centres (CRCCs) is in scope for transition to the ICSS and NDIS and will phase out across NSW in early 2020. While the Young Carer Bursary offers some financial assistance towards educational outcomes and RDPs will offer targeted young carer financial packages, the national volumes of these supports are low compared to the population of young carers. Given that school education is the responsibility of the NSW Government, Carers NSW recommends that the Department take over this role, establishing a targeted tutoring program for, or adapting other existing tutoring programs for disadvantaged school students to explicitly include, young carers.

### **Fund targeted initiatives for young carers in regional and remote areas**

Carers NSW commends the NSW State Government's commitment in the 2019-20 State Budget to improve access and delivery of mental health services in rural and remote communities, the \$50 million investment announced for youth focused projects under the Stronger Country Communities Fund, and the establishment of a Minister for Regional Youth, Regional Youth Strategy, Regional Youth Taskforce and Office for Regional Youth.<sup>33</sup> Around one in three young carers live outside of a major city,<sup>34</sup> and young carers living in these areas are known to experience greater disadvantage than their metropolitan peers, being less likely to complete year 12 and have a post-secondary education.<sup>35</sup>

Young carers are at risk of developing mental health and other challenges as a result of their caring role, and often do not come forward for support. While a range of youth focused online mental health tools exist, in some regional and remote areas coverage is poor, and many young carers come from low income families where smart devices and internet connection may be unaffordable. Young carers across NSW also report to Carers NSW that it is challenging to identify peer support networks in their local area, and lower overall populations and greater distances in regional and remote areas increase the risk of isolation.

Under the NSW *Carers (Recognition) Act 2010*, public sector agencies are required to consider carers' needs in line with the NSW Carers Charter when designing and delivering services that affect carers, and the Charter specifically identifies the need for tailored support for young carers and in regional and remote communities. While supports reaching young people generally are likely to benefit many young carers, in Carers NSW experience, targeting support to young carers and their families increases their likelihood of feeling included and supported by services, and therefore of seeking support. Carers NSW therefore recommends that the newly established youth focused initiatives in regional and remote areas prioritise young carer outreach and support, including assisting young carers to identify and connect with other young carers in their area. Carers NSW also urges the new Minister and Office for Regional Youth to prioritise engagement with young carers and Carers NSW.

### **Promote inclusive recreational activities to young carers**

Article 31 of the United Nations Convention on the Rights of the Child (CRC) outlines children's equal rights to rest, leisure, play and recreational activities. However, research shows that young carers are more likely than their peers to experience social isolation and often face a complex set of barriers that prevent them from exercising these rights.<sup>36</sup> Many young carers find that, as a result of their caring responsibilities, they have limited time and financial resources to dedicate to leisure activities, reducing their ability to socialise with their peers or access respite. Further, some young carers avoid inviting friends to their home due to stigma regarding the appearance or behaviours associated with the condition of the person they care for.<sup>37</sup>

While the ICSS will deliver young carer-specific packages that can be used for respite, as well as peer support opportunities that will likely be inclusive of young carers, Carers NSW is concerned about the potential gaps that may emerge in young carer support, particularly with the limited number of packages available and the current lack of young carer focus in relation to the peer support component of the ICSS.

Carers NSW was pleased that the NSW State Budget for 2019-2020 allocated continued funding to support families and their children in participating in recreational activity programs through Creative Kids and Active Kids, as these programs seek to alleviate the stress families feel in response to the cost of living, allowing for greater social participation in their communities. These kinds of initiatives may also provide indirect respite for young carers supporting a parent or sibling, who are more likely than their non-caring peers to experience socio-economic disadvantage.<sup>38</sup>

To allow young carers continued support in accessing age-appropriate recreational activities that offer indirect respite, it is recommended that the NSW State Government look to implement additional subsidised programs that provide more opportunities for young carers to access indirect respite. Feedback from young carers and their families have identified the benefits of activities that are directed specifically at young carers, particularly as these initiatives allow young carers to share their experiences with peers and realise that they are not alone in their caring situation.

## **4. HELP CARERS ACCESS HEALTH CARE**

Carers access health services both as patients themselves and with and on behalf of the people they care for. In both cases, health services can be complicated to access and may not meet patients' needs. Many patients rely on family members and friends to assist them in accessing health services, and many more are discharged into the care of carers at home and in the community. Adequately funded, carer-inclusive health services are critical in sustaining informal caring arrangements and supporting carer health and wellbeing.

In addition, the NSW Carers Charter stipulates that carers are partners in care, and their choices, views and needs should be taken into account in the assessment, planning, delivery and review of

services provided to the people they care for.<sup>39</sup> As such, carers require increased support, information and resources to better navigate the health system in support of the person they care for.

Carers also require targeted support in order to have their own health and wellbeing needs met. Carers are known to neglect their own health care due to prioritising the health care of those they care for, and this along with the physical and emotional challenges of caring results in a higher than average rate of disability, chronic health conditions and emotional distress.<sup>40</sup> The individual health and wellbeing of carers is imperative to the social and economic sustainability of care in the home and community. When carer health and wellbeing is at risk, there is a greater chance of carers losing the capacity to care or being absent from the home to engage in treatment. The temporary or permanent reduction in capacity to care has an impact at the individual, community and sector levels, including implications for personal relationships, community and health services, and health budgets.

## Recommendations

- Support the identification of carers' health needs when presenting with a patient (pp. 17-18)
- Improve carer support at discharge (pp. 18-19)
- Expanding the provision of carer spaces in hospitals (pp. 19-20)

### Support the identification of carers' health needs when presenting with a patient

According to the Carers NSW 2018 Carer Survey, carers in NSW score up to 28% lower on the Personal Wellbeing Index than the Australian average<sup>41</sup>. In NSW, more than 1 in 3 carers have a long term disability and nearly half of all carers experience high levels of psychological distress. Half of all carers report dissatisfaction with their own health. Further, when assisting care recipients to access health services, only 1 in 4 carers reported they were asked about their own needs.<sup>42</sup>

The increased risk of physical injury as the result of unsafe manual handling is another factor influencing carer health and wellbeing. At least one third of all people with a reported disability in NSW have a profound or severe core activity limitation.<sup>43</sup> Most people with a profound or severe core activity limitation invariably receive self-care and mobility support from informal carers (80% and 89% respectively).<sup>44</sup> Such tasks often require the carer to manually manoeuvre the person by using lifting, carrying, pulling, pushing, or holding actions. Given the many manual tasks that carers are required to perform on a daily basis, combined with a lack of home modifications and insufficient information on proper manual handling procedures, it is unsurprising that carers commonly incur injuries, particularly back injuries.<sup>45</sup>

NSW Health's Information Bulletin, 'Identifying the Carer at Patient Registration' acknowledges carers are more likely to experience physical and mental ill health and disability than the general population. When a carer presents to a health service for the person they care for, carers may not discuss their wellbeing unless practitioners specifically ask. While NSW Health continues to implement new measures to collect carer information, Carers NSW believes more can be done to proactively identify carer health needs and connect carers with the treatment they require. One way to encourage this is to mandate the inclusion of carers in local health district (LHD) Health Care Services Plans, which identify groups at higher risk that the remaining population of poor health.

Free carer health checks are routinely delivered in a range of settings in the UK, including in the home and at pharmacies, community care centres, sports centres and GP practices. Nurses and other health workers conduct assessments of a carer's physical health including BMI, blood pressure, cholesterol and blood sugar as well as mental health assessments.<sup>46</sup> Evaluation data indicates that

health checks led to sustained self-care and healthier behaviours for many carers.<sup>47</sup> Carers reported these checks are an opportunity to attend to their own health needs, and increase awareness of health issues and motivation to follow up with referrals for specialist treatment.<sup>48</sup> Carers also identified benefits to their psychological wellbeing and recognition of the demands of their caring role<sup>49</sup>.

As per our statements in previous Pre Budget Submissions, Carers NSW recommends that carer health checks be piloted in one NSW LHD in the 2020-2021 Budget period to test suitability for state-wide delivery. Carers NSW believes that Community Health Nurses are best placed to conduct the health checks, working closely with other health professionals in order to identify carers through existing clients of services such as the LHD carer programs, Chronic Disease Management Program (CDMP), the Family and Mental Health Carer Program and the Grief and Loss Service. In addition to physical and psychological assessments, carer health checks would also provide an opportunity for Community Health Nurses to refer carers to existing carer supports and services.

This proposed program differs from the NSW Health *Get Healthy Information and Coaching Service* and other community or workplace based health check programs promoted in the Strategy due to its carer-specific design, flexibility and comprehensive nature. The *Get Healthy Information and Coaching Service* is a telephone-based service and is unable to assess a person's blood pressure, BMI, cholesterol or blood sugar and is more suited to people who are already aware of existing chronic health conditions, rather than identifying and treating such conditions. Furthermore, the large proportion of carers whose caring role limits or prevents their participation in the workforce are less likely to benefit from workplace health programs.

Carers NSW envisages significant savings to the health budget with the implementation of holistic health care checks for carers. Identifying and treating physical and mental health conditions are likely to improve carer wellbeing overall, reducing the likelihood of chronic conditions developing and their associated complications which require extensive medical intervention or hospitalisation.

### Improve carer support at discharge

The NSW Carers Charter stipulates that carers are partners in care, and their choices, views and needs should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.<sup>50</sup> The importance of carers is also recognised in the NSW Mental Health Act 2007. In Section 68, 'Principles for care and treatment', the Act stipulates that: (j) the role of carers for people with a mental illness or mental disorder and their rights under this Act to be kept informed, to be involved and to have information provided by them considered, should be given effect.<sup>51</sup>

Many carers in a variety of sectors, including health, mental health and drug and alcohol, experience inadequate information sharing by professionals and a lack of support on discharge, which increases risk to themselves and the person they care for. The 2019 Royal Commission into Victoria's Mental Health System identified that the confidentiality rights of individuals can be overly emphasised to the detriment of providing critical information to carers who are expected to provide care following discharge from health or mental health services.<sup>52</sup> All people, including all care recipients, should maintain their human right to privacy, which must be upheld by professionals in all sectors, including in the health and mental health systems. Care recipient privacy however, must be balanced with a

Laura\* was not informed by the treating team that her son, Max\*, was discharged from a mental health facility, despite the fact it was expected that Max would live with Laura, and receive her support in recovery. Max was discharged to homelessness whilst still being unwell, and was subsequently reported missing for a period of time. The implications of this included a lack of psychosocial stability, limited access to mental health treatment and further negative effect on mental health outcomes.

\*Names changed

carer's right to receive information relevant to their caring role which safeguards both the carer and their care recipient. Carers NSW encourages NSW Health to invest in consultation, policy development and improved discharge support to address this common situation.

The withholding of information from carers that has direct application to their caring role may negatively impact on the quality and sustainability of care provided, placing discharged patients at risk of complications or readmission. A lack of appropriate and ethical information sharing may also have a detrimental impact on care recipient outcomes, particularly with regards to physical and mental health, safety in the community, medication compliance, behaviour needs and potential relapse, and may even result in serious safeguarding risk. The current service environment relies on individuals and families maintaining their own care and support structures, but the effectiveness of these structures can be undermined by a lack of information and transparency.

The 2007-08 National Mental Health Consumer and Carer Forum highlighted that there are multiple barriers to appropriate information sharing, including provider concerns about losing consumer trust, fear of legal consequences, insufficient training opportunities, and a general lack of knowledge with regards to privacy law and subsequent impacts on consumer recovery and carer support.<sup>53</sup> Given the complexity in relation to information sharing, and the ethical implications of decision making with regards to privacy and confidentiality, there is an identified need for improved training and practical support for professionals to promote compliance under current legislation and ensure best outcomes for both consumer and carer.<sup>54</sup>

New Zealand's Mental Health Act requires mandatory consultation with family and carers unless there is evidence to suggest that such consultation is not in the best interests of the consumer. This requirement reflects recognition of the role of family and carers on the basis that they are likely already involved and are often a strong support network. Drawing on this example, NSW Health could adopt various strategies to achieve a balance in supporting consumer privacy and upholding a carer's right to relevant information. This includes investment in education and training for providers to better understand information sharing as a best interest decision, meaningful consultation and disclosure, and disclosure as a means to mitigate risk. It is also recommended that information pathways be clear for consumers, families, carers and sector providers.

### **Expand the provision of carer spaces in hospitals**

Family members and carers provide critical informal support and assistance during a hospital stay. Carers can provide reassurance and support to the patient, facilitate communication with health professionals, support the delivery of optimal, person-centred health care, act as an advocate, monitor health care treatment and compliance, and may assist with practical tasks such as feeding and showering. Carers' contribution to the care of the patient often has a direct benefit to hospital staff, can reduce admission timeframes and has overall economic benefits for NSW Health. Despite these benefits, most hospital spaces are not well designed to accommodate carers in the short or longer term.

In an attempt to assess the need for carer-friendly spaces, Western Sydney LHD conducted a survey with Nurse Unit Managers across ten wards in a major metropolitan hospital. The survey found that between 2014 and 2015, an estimated 477 patients had a family member or carer stay overnight, with a total of 3070 overnight stays.<sup>55</sup> Whilst some accompanied patients in single rooms, family members and carers often slept in chairs next to patients in shared rooms.<sup>56</sup> The estimated average length of stay was four days, with the longest stay being over 30 days. This LHD found that having a family member or carer stay overnight benefits the patient, family member or carer and staff.

This evidence is consistent with reports to Carers NSW of the care provided to care recipients when in hospital. Hospital admissions may be one off and a period of crisis for carers, or may be chronic with issues compounding as carers sacrifice their sleep and comfort to support their family member,

partner or friend. Carers report that accommodation is prioritised within acute care settings; the chronicity of admissions should also be considered when establishing better accommodation for carers in hospital settings. Particular consideration should be given when a carer is travelling from a regional or rural and remote location, and in cases where a patient has become palliative. Designated carer spaces and flexible working hours remove unnecessary pressure from carers who are required to support their loved one in hospital. Cultural needs and expectations may further impact on the admission experiences of carers.

Carers NSW commends the inclusion of 'carer zones' in recent Bankstown and Westmead hospital developments and the implementation of a 'gathering space' for Aboriginal family members to collect as a group and discuss treatment and holistic care needs with the medical team. As other LHDs maintain and redevelop their buildings, Carers NSW recommends similar initiatives be scoped and implemented to meet the needs of local carers.

## CONCLUSION

In light of the many ongoing changes to the carer support sector in NSW, Carers NSW urges the NSW Government to continue monitoring and addressing present and emerging service gaps for carers by considering our Budget recommendations for the 2020-21 financial year. The NSW Government has a strong track record of supporting carers and continues to demonstrate that it takes its legislated obligations of carer recognition seriously.

Carers NSW looks forward to continuing to work with the NSW Government in keeping carers at the centre through prioritising carer recognition, addressing issues arising as a result of sector reform, providing responsive, inclusive support for young carers and assisting carers to navigate health services. The measures we have proposed will ensure that carers and the people they care for continue to have access to critical safety nets as NSW transitions to the ICSS.

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- <sup>45</sup> Ibid.
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- <sup>48</sup> Ibid.
- <sup>49</sup> Ibid.
- <sup>50</sup> Carers (Recognition) Act 2010, Schedule 1 NSW Carers Charter
- <sup>51</sup> Mental Health Act 2007

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