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Ageing, Carers and the Disability Council NSW
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Review of the Carers (Recognition) Act 2010

Carers NSW would like to thank the NSW Department of Family and Community Services (FACS) for the opportunity to provide a submission to the review of the NSW Carers (Recognition) Act 2010. Carers NSW played an instrumental role in the development and introduction of the Act, and for the past five years we have promoted the Act and supported its implementation across a range of sectors.

Carers NSW vision is an Australia that values and supports all carers. As the peak organisation for carers in NSW, our goals are to work with carers to improve their health, wellbeing, resilience and financial security and to have caring recognised as a shared responsibility of family, community and government. Carers NSW considers the Act to be a critical part of advancing these goals. We are pleased to see what the Act has achieved so far, and we are hopeful that following this review, it will be able to achieve even more to improve outcomes for all carers in NSW.

Within this submission we have recommended a range of amendments to the legislation which are based on our research and consultations with carers, Carers NSW staff and stakeholders. Mental Health Carers ARAFMI NSW has also given their formal endorsement. Thank you for accepting our submission and please do not hesitate to contact me if you have any further queries about its content.

Yours sincerely,

Elena Katrakis
CEO
Carers NSW
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1. Introduction

For over 40 years, Australian carers have been calling for greater recognition, inclusion, understanding and support from governments and the community. The introduction of the NSW Carers (Recognition) Act 2010 (the Act) was a historic moment for carers in NSW, representing a commitment to carers at the highest level. For the past five years the Act has been an important mechanism to promote positive outcomes for the 850,000 individuals across NSW who provide care to their family members and friends.

This submission considers the impact that the Act has had so far in NSW, and reflects on the state of recognition for carers today. Our analysis indicates that although the Act’s positive intentions have resulted in increased awareness of carers within the NSW Government, the legislation has not gone far enough to make a real difference to carers, who on the whole continue to feel that their important role is not recognised and acknowledged by services and the wider community.

Whilst the Act’s impact could undoubtedly be strengthened by improved implementation strategies, Carers NSW asserts that the Act itself is inherently limited in its capacity to improve outcomes for carers. Carers, academics and stakeholders have drawn attention to the aspirational nature of the legislation, which has fallen short of establishing provisions for carers which would ensure their needs are prioritised and that they are able to access support.

Carers NSW urges the NSW Government to use this review as an opportunity to move the legislation forward and ‘give it teeth’. Carers NSW recommends significant changes to the scope of the legislation to bring it into line with best practice in carer legislation internationally by giving carers the right to assessment and support in their own right. If given effect, these changes would make real improvements in the lives of carers in NSW.

Carers NSW also recommends a range of smaller refinements to the legislation, to ensure that the NSW Carers Charter (the Charter) reflects best practice for working with carers, that compliance with the Act is properly monitored and that carers are recognised by the full range of services they navigate in NSW.

When the Hon. Andrew Constance MP, former Minister for Ageing and Disability Services, introduced the Carers Recognition Bill 2010 to Parliament he stated:

‘I hope this bill will give some hope to carers, who get on with their work, day in and day out. I hope they understand that this is but a first step.’ [emphasis added]

Carers NSW believes that the next step for the NSW Government should be to give carers more than just a high-level commitment to recognition; it is time for the Act to be used to guarantee recognition and support for all carers in NSW.
2. Impact of the Act

In order to identify how the Act can be strengthened, we must first consider how successful it has been in achieving its objectives. The first five years of the Act have witnessed positive change across the NSW public sector, with many agencies proactively seeking to meet their obligations and improve their support of service users and employees who are carers. Others, however, have been less responsive to, and in some cases unaware of, their obligations under the Act. Many carers and communities also remain unaware of the Act and what it means for them.

2.1 Implementing the Act

Family and Community Services (FACS) has championed the Act within the NSW Government, developing resources and delivering education and training on the Act and Charter, and promoting and modelling best practice for working with carers. The Act has also been complemented by carer specific policy. The NSW Carers Strategy 2014-2019 is the current centrepiece of NSW carer policy and presents a strong, strategic vision for carers in our communities and a blueprint for widespread reform. Together, this carer legislation and policy make NSW a national leader in carer recognition and support.

Since 2010, Carers NSW has partnered closely with FACS in supporting the implementation of the Act by providing education and training to carers, service providers and employers referring to the Act, hosting information on the Act on our website and regularly reminding public sector agencies of their obligations under the Act in our policy submissions and other advocacy work.

2.2 Impact on other legislation

The Act has played an important role in informing the drafting and review of legislation which is relevant to carers. For example, the NSW Mental Health Act 2007, which was recently revised to provide greater rights for carers, upholds the principles of the Charter by acknowledging carers’ expertise and right to provide information, and creating provisions for what information must be communicated to carers.

The recently enacted NSW Disability Inclusion Act 2014 uses the term ‘carer’ with reference to the definition within the Act and refers to the Charter in acknowledging the importance of carers in the lives of people with disability. Carers NSW continues to highlight the importance of consistency with the Act whenever we respond to reviews of policy and legislation within NSW, having most recently done so in our submission to the review of the NSW Guardianship Act 1987.

2.3 Public sector agencies

A number of government departments and other public sector agencies have demonstrated best practice when it comes to fulfilling their obligations under the Act and proactively reflecting the principles of the Charter in their work.

For example, NSW Health have consistently promoted the Act, developing their own Carers (Recognition) Act Implementation Plan 2013 – 2016, with the aim of improving outcomes for carers and the people they care for who access health services, as well as promoting better support for carers working within NSW Health. Carer Programs in each Local Health District have championed
education and promotion at a local level and sought carer representation in service design, management and review. State-wide initiatives such as the eCARERS Learning Program promote a carer inclusive culture across NSW Health. The Act has been also incorporated into the NSW Mental Health Commission’s *Living Well: A Strategic Plan for Mental Health in NSW 2014-2014*.

Transport for NSW has also led by example with their inclusion of Carers NSW and carer representatives in a number of consultative forums and by regularly communicating with Carers NSW about policy and program changes that may affect carers. Three local councils – City of Sydney, Botany Bay and Leichhardt – have also demonstrated their commitment to their consultation obligation under the Act by approaching Carers NSW for feedback when developing local disability inclusion policies. In addition, City of Sydney has sought advice and input from Carers NSW in improving their responsiveness to the needs of employees who are carers.

Despite the responsiveness of some agencies, Carers NSW continues to bring many others to account by reminding them of their obligations. In our advocacy work, we encounter numerous examples of agencies, including human service agencies, who do not consult carers or carers’ organisations about policies affecting carers, do not reflect an understanding of the Charter in their work or HR policies, and do not report on carer related issues in their annual reports.

Carers NSW has also received phone calls from a number of carers working for public sector agencies who feel they have experienced discrimination due to their caring role, or as a result of workplace practices found it difficult combine work and care. Nevertheless, the Carers NSW 2014 Carer Survey found that the employment experiences of respondents working in the public sector did not differ greatly from those working elsewhere, except that public sector employers appeared to perform better overall with regard to providing carer’s leave and flexible working conditions. While these accommodations are not necessarily related to implementation of the Act alone, they are a positive sign for carers working in the public sector.

### 2.4 Carers’ awareness of the Act

Another measure of the success of the Act is whether carers themselves are aware of it. According to our 2014 survey, around one third of respondents had heard of the Act, while less than one quarter had heard of the Charter. Just over one third of respondents indicated that they had heard of the NSW Carers Advisory Council (the Council).

Significantly, respondents who worked in the public sector were more likely to have heard of the Charter, suggesting that some public sector agencies are communicating these principles effectively to their employees. However awareness of the Act and the Council were not notably greater among public sector employees. These findings indicate that there is still a long way to go in increasing awareness of the Act within the public sector and broader community.
3. The case for change

In 2016 carers are contributing more to their communities than ever before. In August 2015 we heard new evidence from Deloitte Access Economics that demand for family and friend carers is at an all-time high, and set to increase. The latest data from the Australian Bureau of Statistics shows that two in five primary carers in Australia are spending 40 hours or more per week caring.

Despite the ever increasing contribution of carers to our state, carers in NSW continue to be socially and economically marginalised. When Australians take on a caring role they are likely to face significant financial hardship, as well as challenges to their mental and physical health. Whilst this submission will not go into this evidence in detail, some key figures reveal the extent to which inequities persist for carers in NSW.

3.1 Socio-economic status

More than one third of carers in NSW live in low income households, and a similar proportion receive their main income from a government pension or allowance. Both of these figures are more than fifty per cent for primary carers. Almost half of the carers in NSW are not in the workforce, or 60 per cent of primary carers, and those who are employed are more likely than non-carers to be working part-time. As a result, carers frequently face financial pressure and socio-economic disadvantage from limited income, savings, assets and superannuation.

3.2 Wellbeing

Carers are more likely than non-carers to experience reduced physical, mental and emotional health. The latest edition of What Makes Us Happy, the report on the Australian Unity Wellbeing Index, has re-iterated its disturbing finding that carers have the lowest wellbeing of any group, including the unemployed and homeless. This is consistent with the findings of the 2014 Carer Survey, in which four out of five respondents reported below average wellbeing. Carers are also more likely to have a disability or chronic health condition themselves, and are more likely than the general population to experience depression and anxiety.

3.3 Benefits of caring

Whilst these figures are alarming, our Carer Surveys have also revealed that carers consistently experience positive outcomes from their caring role. In spite of the many challenges they can face, carers don’t want to be pitied, and many report that caring makes them feel useful, gives meaning and purpose to their lives, allows them to learn new skills and strengthens their relationships.

3.4 Carers’ views

Carers know that what they do is critically important, but do not necessarily feel that they are recognised or acknowledged by services and the wider community. Preliminary data from our 2016 Carer Survey, which is still being conducted at the time of writing, reveals the extent to which carers continue to feel marginalised, disempowered, isolated and forgotten by their communities and by governments. Below is a snapshot of what carers said when asked to comment on whether their caring role is recognised and valued by their community:
‘Although we are saving the government millions of dollars, we are not valued in society by the community or government.’

‘The government does not appreciate and realise how much money carers save tax payers and turn a blind eye to just how hard and lonely being a carer is.’

‘I feel that my caring role is recognised and valued by the people I care for. I think the community in general has no idea about my caring responsibilities.’

‘I feel that I [sic] am totally de-valued and ignored by the NSW State Government.’

‘I don’t think anyone in the community know [sic] I’m here.’

‘I think a great deal of lip service is paid to the value of working carers but the true heart attitude is seen in the actual dollars apportioned to providing respite for them.’

‘I feel lost and ignored.’

‘Definitely [sic] by my Community but not by the government or outside community who have no experience of the life you live when you are caring for a pwd [person with disability].’

‘The rhetoric is not acted upon. I don’t need awards or recognition… I need time out.’

‘maybe acknowledge, but not understood [sic], how much time it absorbs physically and mentally.’

‘Disappointed with the government’s use of platitudes which make them look and feel good. Their lack of understanding at how much emotional energy and time it takes to jump through the administrative [sic] hoops….General community only values what the government values and vice versa.’

‘I think that people I know feel sorry for me but I wouldn’t say I feel valued by the community in general.’

‘My situation is very thankless but friends & community express appreciation for what I endure & encourage me.’

These comments send a strong message to governments and communities- we need to do more to recognise and support carers.
4. Recommendations for reform

Improving support for carers must be addressed as an urgent priority, and carer legislation is an important mechanism to pursue this goal. This section outlines our key recommendations for amending the Act and expanding its reach.

4.1 Definition of a carer

Carers NSW supports the current definition of carer in the Act and considers that the level of detail provided is helpful in clarifying who is, and who is not, a carer. However, we believe that some of the wording could be simplified and that some further elements could be added to clarify the definition.

The term carer is often used by people within the NSW Government and by the broader community, especially the media, to refer to paid care workers, as well as foster carers, kinship carers and parents and grandparents of children who do not have additional care needs. Furthermore, carers often remain hidden because they, and the services they engage with, are not aware that they meet the definition.

While this misuse of the term carer could be addressed partly through stronger implementation of the Act, Carers NSW believes that clarifying and simplifying the definition of carer in the Act is an important first step. In the box below, we have made our suggested amendments to the definition in green text.
(1) For the purposes of this Act, a person is a carer if the person is any individual who personally provides ongoing personal care, support and assistance to any other individual who needs it because that other individual:
   (a) is a person with disability within the meaning of the Disability Inclusion Act 2014, or
   (b) has a medical condition (including a terminal or chronic illness), or
   (c) has a mental illness, or
   (d) has a drug or alcohol dependency, or
   (e) is frail and aged.

(2) Despite subsection (1), a person is not a carer for the purposes of this Act in respect of care, support and assistance that the person provides:
   (a) under a contract of service or a contract for the provision of services, or
   (b) in exchange for an income (excluding government income support payments)
   (c) in the course of doing formal voluntary work for a charitable, welfare or community organisation, or
   (d) as part of the requirements of a course of education or training.

(3) To avoid doubt, a person is not a carer of another person for the purposes of this Act merely because the person:
   (a) is the spouse, or de facto partner, of the person, or parent, guardian, child or other relative, or
   (b) is the parent, guardian, child or other relative of the other person, or
   (c) lives with the other person.

   a person in need of care, support and assistance as defined in subsection (1).

(4) A person is not required to meet any of the following criteria in order to be considered a carer for the purposes of this Act:
   (a) identify with or use the term carer, or
   (b) be the only or main person providing care, support and assistance, or
   (c) have a formally appointed role under other legislation, such as the Guardianship Act 1987 or the Mental Health Act 2007, or
   (d) be in receipt of the Carer Payment or Carer Allowance from the Department of Human Services, or
   (e) live with the person they care for.
4.2 Objects of the Act

The capacity of the Act to promote equitable outcomes for carers is inherently limited by its objects. Carers NSW welcomed the proposed benefits for carers flowing from the implementation of the Act and Charter, such as increased opportunity for workforce participation; increased opportunity for social inclusion, the ability to provide input to public service policy and program development on matters that affect carers, and referral to appropriate support services.

However, Carers NSW believes that these potential benefits will not be fully realised if the purpose of the Act is limited to recognition and acknowledgement of carers. Carers NSW recommends that the objects of the Act be expanded to reflect a more ambitious purpose- to promote improved outcomes for carers in their caring roles.

4.3 Establishing rights for carers

Whilst carers in NSW have some protection under the law (most notably in the workplace through anti-discrimination legislation), carers in NSW are generally unprotected, and their right to care without facing adverse outcomes is not legally established. Carers who call the Carers NSW Carer Line frequently query, ‘what are my rights?’ in regards to their situation. Most often, the answer is that they do not have any rights- the Act only contains best practice principles, and in many cases advocacy services are only available to the person they care for.

4.3.1 UK legislation

By contrast the UK has enacted legislation which gives carers clearly defined and meaningful rights since the mid-90s. The Carers (Recognition and Services) Act 1995 provided individuals who undertake a substantial amount of care on a regular basis with the right to ask for an assessment of their needs, an assessment which would then be taken into account in the delivery of services to the person that they were caring for. The Care Act 2014, implemented in April this year, superseded this Act and has given an even larger cohort of carers a clear right to support, effectively ‘putting carers on an equal footing to those they care for’.

Professor Luke Clements, a leading expert on UK community care law and the rights of carers, wrote in 2013 that carers are ‘stretched to breaking point’ and drew attention to the limitations of carer recognition legislation in making genuine improvements to the lives of carers without dedicated resources. He writes:

‘the general response of governments...has been tokenistic: involving in large measure the enactment of opiate legislation – for example, of the relatively bland ‘carer recognition’ type. These are essentially rhetorical measures, heavy on process and exceedingly light on substance: responses that place little or no strain on the public purse.’

In light of such observations, Carers NSW strongly encourages the NSW Government to make a genuine difference to the lives of carers by enacting provisions which give carers the right to support.
4.3.2 The economic case

A recently published report by Deloitte Access Economics provides compelling evidence that any investment in supporting unpaid carers is more than compensated for by the contribution they make to our economy. The economic value of informal care in Australia in 2015 estimated that Australia’s carers will provide 1.9 billion hours of care in 2015, and if we paid for that care it would cost $60.3 billion, or 3.8 per cent of our Gross Domestic Product.

Using the same economic modelling, Carers NSW has made a conservative estimate that the replacement cost for carers in NSW is $17.7 billion. Carers NSW urges the NSW Government to take these findings into account when considering changes to the legislation which would provide carers with a right to support.

4.3.3 National reforms

Establishing rights for carers is particularly important in the context of ongoing sector reform. The provision of support to carers continues to be mediated by the changes and transitions which are occurring across all sectors, particularly as the National Disability Insurance Scheme (NDIS) is rolled out and an Integrated Plan for Carer Support Services is developed by the Department of Social Services.

These nationwide changes have the potential to positively transform the caring role, however there remains confusion surrounding the services and support which will actually be available to carers. Although carer supports and entitlements are being worked on at a national level, legislating these within NSW throughout the transition is surely worthwhile.

The rhetoric of choice, control and person centred support has achieved prominence for services working with people in NSW with disability, older people and other service users to differing degrees. For example, the Disability Inclusion Act 2014 recognises the right of people with disability to be in control of their lives and outlines how supports for people with a disability will be funded.

However carers’ own right to choice, control and support has been largely absent from NSW Government policies and programs, despite a strong body of evidence which highlights the benefits of supporting carers. Strengthening legislation to provide carers with real rights will provide a guarantee for carers that they will not be left behind as sector reform progresses.

4.3.4 A model for reform

Under the Carer Act 2014 (UK) carers are entitled to receive an assessment regardless of whether they have requested it, whether their needs for support are ‘regular or substantial’ and regardless of their financial resources. This right to assessment is independent of the person with care needs’ right to assessment.

The Act also legally requires relevant authorities to meet a carer’s need for support- with no charge for carers with financial resources below an identified limit. If a carer meets the eligibility criteria, the relevant authority must work in partnership with carers to prepare a ‘support plan’ for carers, which determines how their needs will be met and if they will be eligible for a direct payment.
The Care Act 2014 sets a new benchmark for carers’ rights internationally, and extends rights for carers which commit the Government to allocating resources to carers to ensure that these rights are upheld. Carers NSW encourages the NSW Government to lead the way in Australia by introducing legislation which gives carers rights to their own assessment and support to address needs that have been identified through this assessment. In this way the NSW Government could continue their reputation as a national leader in carer recognition and support.

4.3.5 Right to assessment

Best practice in carer inclusion is to provide a formalised carer assessment, separate to that of the person with support needs, which takes into account the carer’s own goals and needs. Such an assessment would consider carers’ health and wellbeing, and assess capacity to continue caring at the current level. Carer assessment has previously been recommended by the Productivity Commission in its final report on the Disability Care and Support Inquiry and was highlighted in the Commonwealth Who Cares…? Report.\textsuperscript{xv}

The NSW Carers Charter currently espouses a number of principles which could be promoted further by introducing a right for carers to assessment. These principles include that carers’ health and wellbeing should be given due consideration, carers should be referred to appropriate services to assist carers in their caring role, and carers are to be acknowledged and recognised as having their own individual needs within and beyond their caring role.

Carers NSW recommends that the NSW Government embed carer assessment as a formal process mandated by the Act and direct resources toward supporting service providers to consistently implement carer assessment and promote it to carers. Carers NSW suggests that these provisions make it clear that carer assessments should be considered in conjunction with assessments of the care recipient, to inform a holistic planning process.

4.3.6 Right to support

The NSW Carers Charter also states that support for carers should be ‘timely, responsive, appropriate and accessible’, however this is far from a reality for much of the carer population in NSW. The Carers NSW 2014 Carer Survey found that over 40 per cent of respondents had nobody else who helped them care. One third said there would be no one available to help them if they were ill or needed a break.\textsuperscript{xvi} In some cases this jeopardises the caring role and carers are unable to continue caring. More commonly it results in disruption to workforce participation, finances, health, wellbeing and social inclusion, highlighted in Section 2 of this submission.

When carers have access to support in their own right, such as the National Carer Counselling program, or carer support groups, these adverse outcomes can be reduced.\textsuperscript{xvii} The NSW Government currently funds a number of programs that provide supports and services directly to carers, including information, respite, support coordination and peer support groups. The Australian Government also funds a number of programs with direct supports for carers. However, as sector reform progresses, a number of service gaps are emerging for carers.\textsuperscript{xviii}

Most funded programs currently delivering support to carers are in scope for either the NDIS or Commonwealth Home Support Program (CHSP). While an Integrated Plan for Carer Support Services is currently under development at a national level, the scope of funded carer supports in NSW into
the future remains unclear. Carers NSW believes that the NSW Government has a responsibility to demonstrate best practice in carer support throughout this sector transition and to advocate for carer recognition and support at a national level. Enshrining carer rights in NSW legislation is an important part of this, and Carers NSW would hope that the amended Act could pave the way for future expansion of the equivalent Commonwealth legislation.

One carer’s comment in the 2016 Carer Survey demonstrates the level of concern amongst carers in the current climate:

‘Increasingly I am getting the feeling that Government is not interested in supporting carers - programs for carers have been scrapped and the focus is on the person cared for. This has increased my anxiety for the future because I feel I will no longer get the support I need to care for my loved ones who need me on a daily basis.’

Carers NSW suggests that the revised Act provide carers with the certainty that they will have assistance in their caring role. Using the same principles that are applied to other service users, carers should be provided with support that is person-centred, whilst at the same time recognising the importance of the caring relationship. A carer support plan should be developed in partnership with the carer following carer assessment, and be accompanied by an outline of how these identified needs will be met with Government resources where appropriate.

4.4 Strengthening the NSW Carers Charter

Carers NSW believes that the Charter is a comprehensive and useful set of principles for the treatment and consideration of carers. Carers NSW suggests that the Charter be refined and simplified to ensure that it is rights focused, accurately reflects best practice with carers, and can be easily understood and implemented by service providers and relevant agencies. Carers NSW suggests that a rewritten Charter should incorporate a number of key changes listed below.

4.4.1 Diversity of carers

Carers NSW believes that the importance of considering carers’ cultural and linguistic diversity should be emphasised in the Charter, and recommends that a stand-alone principle be dedicated to these matters, rather than having them simply reflected in the list of factors in principle f), as it is now. Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse backgrounds provide care in specific cultural contexts which require consideration at all levels of policy and program development and service delivery.

Additionally, the specific needs of carers who identify as lesbian, gay, bisexual, transgender or intersex should be added to the list of diverse groups in principle f), reflecting the particular needs of carers in these communities for whom the challenges of the caring role may be intensified by exclusion and experiences of discrimination.

4.4.2 Partners in care

One of the key concerns of carers when engaging with services is inadequate communication or involvement in the care of their loved one. The importance of including carers as partners in care and of two-way information sharing should also be reflected in a refined Charter.
Australia’s carers, the national equivalent of the NSW Carers Charter, has given effect to this principle, establishing that carers:

'should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.'

The importance of considering carers as partners in care is recognised nationally as a critical component of safe and quality health care through the National Safety and Quality Health Service Standards. These Standards are currently under review and the Australian Commission on Safety and Quality in Health Care has indicated that further evidence of carers’ important role in promoting improved health outcomes informed the review of the Standards.xix

The concept of carers as partners in care is also reflected in NSW through innovative programs such as the Top 5 Initiative, and through legislation. For example the Mental Health Act 2007 states 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.’

Carers NSW considers it appropriate for the Charter to specifically address the principle of including carers as partners in care, and suggests it is incorporated into principle m).

4.4.3 Choice and control

Given the current emphasis on choice and control for people with disability in NSW, choice and control for carers also warrants a greater focus in the Charter. Principle j) already refers to carers’ choices in their caring role; we recommend that this principle also refer to carers’ right to end their caring role if they prefer.

As the NSW disability sector transitions to the NDIS, there is a risk that the concept of carer support will be narrowed to sustaining the caring role, which is a priority of the Scheme. However, Carers NSW believes that NSW legislation should reflect the importance of carers’ needs and wellbeing in their own right by ensuring they have a choice about whether or not to continue in their role.

4.4.4 Simplifying the Charter

Carers NSW also suggests that the Charter be generally simplified to clarify statements which do not convey a clear meaning (eg. principle e)) and to consolidate statements with similar sentiments (eg principles c) & j); principles g) & h); principles f) & k); principles d) & l)). We also suggest the Charter is re-ordered to flow more logically (eg. it would make sense for principle l) to follow principle d), and for principle m) to follow principle c))

4.5 Improving accountability

4.5.1 Centralised responsibility

In order for the Act to be effective, Carers NSW believes it should sit under the jurisdiction of a more central agency than FACS, such as the Department of Premier and Cabinet or the Public Service Commission. This placement would better enable a whole-of-government approach to implementing
the Act, provide greater accountability and promote increased buy-in from other agencies. This central agency could be responsible for receiving regular reports from all agencies on their implementation of the Act, and subsequently report back to the Carers Advisory Council on the sector’s performance and any emerging issues.

4.5.2 Carers Advisory Council

Carers NSW believes that the Carers Advisory Council (the Council) has an essential role in providing expert advice to the Government on a range of carer related issues. However, we believe that its effectiveness could be increased if established as an independent council reporting to the Minister. Under this model, the Council would be facilitated by a non-government associated co-chair, and run similarly to equivalent councils, such as the NSW Ministerial Advising Committee on Ageing.

Carers NSW also believes that the functions of the Council should be expanded under the Act, so that the Council has additional capacity to monitor its implementation. The central agency responsible for implementing the Act (see Section 4.5.1) could be required to regularly report to the Council on the sector’s performance against its obligations under the Act. Additionally, the Council could monitor the broader uptake and impact of the Act across the community, working in partnership with the sector, the responsible agency and the NSW Ombudsman, as recommended in 4.5.1 and 4.7.

4.6 Extended coverage

Carers provide support to a diverse group of people, and the services that they interact with are equally diverse. A wide range of non-government organisations across NSW provide support to carers and the person they care for, and these display varying degrees of carer awareness and recognition.

Carers themselves have identified extension of the Act to cover non-government services as a high priority in consultations on the Act. In order to ensure that carer recognition is promoted by the full range of services that carers use, Carers NSW recommends that the legislation create obligations for all services which work with carers and/or the person they care for. Carers NSW suggests that linking carer recognition and inclusion to accreditation and funding may be one strategy to extend the obligations within the Act.

Extended coverage of the Act will be particularly important as the NSW Government ceases to provide disability services in the transition to the NDIS, as all disability services will be provided by the non-government sector.

4.7 Overseeing carers rights

In order for greater carer recognition and support to be achieved, carers must be empowered to assert their rights, and must therefore have clear avenues to report services and agencies who are not fulfilling their duties under the Act. Carers’ capacity to do this is currently limited, and avenues for feedback are fragmented across sectors and focused on the person with care needs.

Carers NSW recommends that amended legislation provide a dedicated, independent avenue for carers to assert their rights. Carers NSW notes that the NSW Ombudsman plays an important role in
overseeing Government and community services, including investigating complaints and inquiring into major issues, as well as more specific requirements set out by legislation such as the Disability Inclusion Act 2014. As an ‘independent and impartial watchdog’ it appears to be ideally placed to review the delivery of government and community services with regards adherence to the Act and Charter.

Carers NSW recommends that an independent body, such as the NSW Ombudsman, be authorised to investigate complaints under the Act and oversee the implementation of the Charter in services across NSW.

5. Summary of recommendations

Minister for Disability Services, the Hon. John Ajaka MP has articulated his commitment to ensuring ‘we have the right laws in place’ for carers. Carers NSW has made a range of recommendations in this submission which we believe will ensure that the Act contains the right components to recognise and support carers in NSW.

Carers NSW has recommended that:

- the revised legislation establish carers’ rights to assessment and support
- the Charter be simplified and revised to emphasise the need to support diverse carers and consider carers as partners in care
- responsibility for the Act be centralised within the NSW Government
- the Council be established as an independent Council with extended functions
- non-government organisations that provide services to carers and/or the person they care for be covered by the Act
- an independent body be authorised to investigate complaints and oversee the implementation of the legislation

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iv Ibid. Low income is defined as residing in a household with equivalised gross household income in the lowest two quintiles.

Ibid.

Ibid.

Ibid.


