Carers WA response to
WA Carers Strategic Framework
February 2016

*Working in partnership with Western Australian carers and their families,
service providers, peak bodies and government agencies*

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1.   Introduction

1.1   Carers WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged[1]. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour. Illness and disability are non-discriminatory and the caring role can be borne by any individual at any given time, regardless of socioeconomic status, age or location.

Key demographic trends point to a significant increase in the demand for carers. With advances in healthcare people are living longer including those with frailty, chronic illness or disability. According to the Australian Government's Taskforce on Care Costs, established in 2007 "The proportion of Australia's population aged over 65 years is set to increase from 13.4 per cent to 20.5 per cent by 2027"[2] The number of people aged over 65 is expected to double by the year 2054. As such there will be fewer people of working age. The number of people of working age compared to those 65 and over is reducing and is expected to fall from 7.3 in 1975 to 2.7 people in 2054[3]. Demographic trends strongly indicate that the demand for caring is going to increase. The economic and social sustainability of this situation will depend upon the ability of carers to combine work and care and to enter or re-engage with the workforce when their caring role ceases or is reduced.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems. A recent report undertaken by Deloitte, Access Economics determined the replacement value of the care undertaken by carers in Australia to cost $60.3 billion per annum[4]. Providing supports to carers is an effective means to reduce the financial costs to the Government and taxpayers as well as the social costs to the wider community.

In order to address these challenges cultural shifts are required within the community as well as across government, non-government services and the private sector. Such shifts require workplaces and other services to be aware of the role and needs of carers. In order to achieve this, it is necessary to provide appropriate and flexible supports to assist carers during the course of their caring role, whilst also meeting their needs if and when their role reduces or ceases. In addition to the benefits to service improvement there is considerable opportunity to improve community and workforce participation through state and regional initiatives that target and improve service availability, particularly in the regions. Such initiatives could have additional benefits, by stimulating growth, improving productivity and enabling the development of a more sustainable economy and equitable communities state-wide.

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[1] Carers Australia, www.carersaustralia.com.au

[2] Taskforce on Care Costs 2007,The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability

[3] Treasury Intergenerational Report 2015, Commonwealth of Australia, page viii

[4] Access Economics. 2015. The Economic Value of Information Care in 2010. Deloitte and Carers Australia, Canberra.

Carter Statistics

⟩ There are 2.86 million unpaid carers in Australia. More than 825,000 carers are primary carers[5].

⟩ There are more than 320,000 family and friends in a caring role – 1 in 8 Western Australians[6].

⟩ Almost 80,000 carers live outside of the metropolitan area in Western Australia[7].

⟩ 53.6 percent of primary carers aged 15-64 years in Australia are employed, compared to 79.4 per cent of non-carers[8].

⟩ The Australian Government 'Intergenerational Report' noted that in 2007 there were 5 people of working age in Australia to support every person 65 years and over. The report also notes that this will decrease to 2.4 by the year 2047[9].

⟩ It has been estimated that an extra 3 percentage points of participation among workers aged 55 and over would result in a $33 billion boost to GDP – or around 1.6 per cent of national income[10].

⟩ Researchers suggest that only 4% of young carers between the ages of 15 to 25 are still in education, compared to 23 % of their peers[11].

⟩ 24.1% of Carer Payment recipients are on incomes below the poverty line[12].

⟩ Almost 45% of carers in very remote areas are Aboriginal and/or Torres Strait Islanders[13].

⟩ Over 69.7% of primary carers are women[14].

⟩ More than 17,100 carers in Western Australia are under 18 years of age[15].

⟩ An estimated 42,900 carers in Western Australia are 65 years of age or over[16].

[5] Access Economics. (2015). The Economic Value of Information Care in 2010. Deloitte and Carers Australia, Canberra.

[6] ABS (2015). General Social Survey 2014: Summary Results, Australia.

[7] ABS (2009). Disability, Ageing and Carers, Australia: State Tables for Western Australia.

[8] Ibid.

[9] Australian Government, 2007, Intergenerational Report, p. 17.

[10] Deloitte Access Economics (2012) Increasing participation among older workers: the grey army advances, Report prepared for the Australian Human Rights Commission, pg i.

[11] Carers Australia, (2011), Young Carers in Education – supporting rural and remote young carers. Pg 13.

[12] ACOSS. 2012. *Poverty in Australia: ACOSS Paper 194*. ACOSS, Canberra.

[13] Edwards et al, op. cit.

[14] ABS (2012). Disability, Ageing and Carers, Australia: Summary of Findings, 2012. Commonwealth of Australia, Canberra.

[15] Australian Government, 2007, Intergenerational Report, p. 17.

[16] ABS (2009). Disability, Ageing and Carers, Australia: State Tables for Western Australia. Commonwealth of Australia, Canberra.

⌡ Across Australia, research suggests more than a third of carers have severe or extremely severe depression. In the largest ever study of carers in Australia, carers recorded the lowest levels of wellbeing of any social group[17].

1.2 Carers WA Survey

In August 2015, Carers WA developed and circulated a survey to our members and networks. The survey was open from 27 August to 18 September, and the results have been used to inform Carers WA's response to the WA Carers Strategic Framework (Strategic Framework).

The questions, respondents and key findings of the survey can be found in Appendix A.

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[17] Cummins, R., J. Hughes, A. Tomyn, A. Gibson, J. Woerner and L. Lai. 2007. *The Wellbeing of Australians – Carer Health and Wellbeing.* Report 17.1. Deakin University, Melbourne.

2.   The WA Carers Strategic Framework

2.1   Introduction

Currently, there is confusion in language between a 'strategy' and 'strategic framework'. At different stages, the document and questionnaire refers to a strategy or a strategic framework. It is also unclear that whether the current version of the document is structured purely for consultative purposes or will shape the core of the final document for public release.

To our understanding, the difference between a strategy and strategic framework is that a framework will include more than what we want to achieve. It will outline how things will be achieved, in what timeframe and who is involved in its delivery. It should also be flexible and responsive to the continually changing environment that the caring sectors are experiencing.

As an example, the National Carer Strategy does not outline how the strategy will be implemented. However, there is an accompanying action plan for the National Carer Strategy. In order to achieve the most purposeful and efficient piece of state government policy for WA, a strategic framework should be used as the most appropriate solution.

The sections that are not currently included in the Strategic Framework, which Carers WA has provided recommendations on are:

⟩ Development of a Strategy Document

⟩ Endorsement from the Minister

⟩ Collaboration

⟩ Measurement

⟩ Implementation of the Strategic Framework.

There are a number of evidence based recommendations in the Carers WA Pre-Budget Submission 2016-17[18], which we would like to be considered within the Strategic Framework. The submission focuses on Working Carers, Hard to reach Carers and Empowering Carers. It includes recommendations covering a number of key areas where there are gaps for carers in WA, including carers from specific cultural backgrounds and carers in regional areas.

Recommendation 1: Incorporate proposals from the Carers WA Pre-Budget Submission 2016-17 into the Strategic Framework.

Carers WA are developing a series of 'Caring in Focus' policy position papers, these highlight a number of areas where there are gaps in research or services. These recommendations have been incorporated under the Priority Areas.

2.2   Development of a Strategy Document

It would be beneficial for readers of the Strategic Framework, if there was a more concise *Strategy Document* of approximately 4-8 pages. This would allow senior executives and busy carers, who have limited time capacity, to access the key points of the Strategic Framework. It would give a clear outline of what will be achieved.

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[18] https://www.carerswa.asn.au/resources/2015-Oct-Prebudget-Submission-2016-2017-Final.pdf

This could include a graphical representation to outline how the different elements work together, i.e. vision, outcomes and priority areas. A graphic that outlines the Strategy has been used in other jurisdictions, such as the '*NSW Carer Strategy 2014-2019'*. The example from the NSW Carer Strategy has been included in Figure 1. In addition, see Figure 2 for an excerpt from the content of the current Strategic Framework, which has been developed by Carers WA, as an example of how the WA Strategic Framework could be graphically presented.

Recommendation 2: Develop a *Strategy Document*.

Recommendation 3: Develop a graphical representation of the connectivity between the vision, priority areas and outcomes.

Figure 1: NSW Carer Strategy 2014-2019, pg. 7

Focus areas	Planned reforms	Expected outcomes
Employment & education	• Increase the use of existing workplace flexibility by carers and their employers • Enable carers to recognise the skills and expertise they bring to employment and training • More young carers receive support at school to transition to further education and employment	Carers have choices and opportunities to participate in paid work Young carers complete school and transition to further education and employment
Carer health & wellbeing	• Improve the design and delivery of services and programs in ways that make it easier for carers to look after their own health and wellbeing	Carers experience good health and wellbeing
Information & community awareness	• Embed and improve information for carers in the trusted systems they frequently use • Create positive media campaigns that portray carers as real people • Increase the number of people with an understanding of carers lives	Carers are able to easily access information when they need it Carers feel the broader community understands their experience
Carer engagement	• Continue to improve the ways we involve carers as partners in the care delivered to their loved ones • Greater involvement of carers in local decisions about the design and delivery of services	Carers are involved in decisions that affect them and the people they care for
Evidence base	• Better use is made of the available data and research to create evidence that will shape policy and programs	Carers policy and practice is informed by quality evidence

Source: NSW State Government, Department of Family and Community Services.

Figure 2: Example graphical representation of the WA Carer Strategic Framework

VISION	Priority Area		Strategies	Outcomes
	1	Awareness, identification, and recognition	**1.1, 1.2, 1.3:** Identify and raise awareness of carers **1.4:** Promote carers' contribution to the community **1.5:** Meet the needs of carers from diverse backgrounds	• Carers contributions will be recognised and respected by the community • Carers will have the same life choices and opportunities as all Western Australians
	2	Respected partners in care	2.1 2.2 2.3	
	3	Supporting carers	3.1 3.2 3.3	
	4	Participation in education and employment	4.1 4.2 4.3	
	5	Data and evidence	5.1 5.2	

Source: Carers Association of WA Inc.

2.3 Endorsement from the Minister

An endorsement from the Minster in the form of a Foreword, would highlight the high level commitment to the principles of the Strategic Framework and the delivery of its priorities. In a process that seeks to engage other government agencies the support of the minister is critical in gaining co-operation and sends a positive message to WA carers.

Recommendation 4: Include a *Foreword* from Minister Simpson in the final documentation produced.

2.4 Collaboration

With the understanding of a difficult economic environment and the cross-sector nature of carers' supports, there is a distinct need for stakeholders to work together when supporting carers. Ensuring the Strategic Framework identifies the relevant agencies for each strategy, will give ownership across government, and provide incentives for collaboration. We believe this would entail the Department of Local Government and Communities (Department) being the sponsor, and supported by other relevant agencies.

It would also be preferable when the Strategic Framework has been finalised, for each government agency to develop their own *Carer Action Plan*, which will incorporate all the relevant strategies and collaborations.

Recommendation 5: Inclusion of key stakeholders for each strategy and/or priority area of the Strategic Framework.

Recommendation 6: The Strategic Framework recommends that each relevant government agency develop a *Carer Action Plan*.

2.5   Measurement

An outline of how the Strategic framework will be evaluated should be included in the document itself. Ideally, an evaluation framework would be developed alongside the Strategic Framework, to ensure that the relevant data sources are available and suitable to the needs of the evaluators. This will ensure that progress toward the outcomes can be measured, reviewed and updated on a regular basis. This will also allow for the Strategic Framework to be updated based on contextual changes, such as new legislation, changes to the National Disability Insurance Scheme, Commonwealth Aged Care funding arrangements and national individualised mental health funding packages.

Recommendation 7: Include a section outlining how an evaluation of the Strategic Framework will be completed, i.e. *Evaluation and Monitoring*.

2.6   Implementation of the Strategic Framework

As part of the Strategic Framework, a section should be included that explains how it will be implemented. As described above, the benefit of a Strategic Framework compared with the Strategy, is the level of detail it can provide. The inclusion of how the strategy will be achieved, would give the sector a much clearer outlook of the direction that the Department is working towards.

In section 5 of the document titled '*Carers Strategy Working Group – Outcomes*', circulated by the Department on 1 July 2015 to the Carers Strategy Working Group, there was a reference to Partnership as a "key element" in implementing the Carer Strategy (as called at that time). The following was contained in that document:

> *"Carers, representative organisations, government departments and other relevant entities are actively involved in developing cooperative actions to deliver the strategy."* [19]

In the current version of the Carer Strategic Framework, there is no reference to such Partnership, or actions to deliver the Strategy. Carers WA feel it is an important initiative to be included in the document. In terms of implementing the Strategic Framework a number of practical measures could be included in the document which are recommended below.

Recommendation 8: Establish a dedicated team of staff within the Department to drive the implementation of the Strategic Framework. For more detail, see page 9 of the '*Carers WA Pre-Budget Submission'*.

Recommendation 9: Establishment of a Steering Committee for the implementation, which would include a range of carers with lived experience (e.g. mental health, aged care, health, disability and alcohol and other drugs).

Recommendation 10: Establishment of a Cross Government Committee that would include all relevant agencies that have endorsed the Strategic Framework.

Recommendation 11: Reference to a range of good practice policies and templates for inclusion of carers in planning of services. This would be for both improved carer participation

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[19] Department of Local Government and Communities, 2015. Carers Strategy Working Group – Outcomes, section 5.

in service assessment, planning, delivery and review, as well as improved services specifically for carers.

Recommendation 12: Include a section in the document for how the Strategic Framework will be implemented and attach a detailed Implementation Plan as an Appendix.

3. Feedback on the Draft Strategic Framework

3.1 Language

Throughout the draft there is language used which may not reflect a person centred approach; a carer is a person first and a carer second. Language such as 'person in a caring role' should be used, or at least acknowledged at the beginning of the document. In addition using the word "carers" in preference to "they" throughout the document.[20]

Include the following dot points on page 6 under 'Carers enable the people they care for' to:

) achieve and maintain a quality of life

) have choice and control.

The reference to the Deloitte report titled '*The economic value of informal care in Australia in 2015*',[21] on pg. 6 of the Strategic Framework refers to informal/primary care, whereas the report is derived from a composite of primary and non-primary care hours (Table 2.3).

The following sentence is noted as an important recognition of the combined nature of the lives of the people with care needs and their carers.

> *"It will recognise that the lives and needs of carers and the people they care for are entwined, but they are not the same."*[22]

3.2 Comment on Draft Introduction

The introduction to the Draft Strategic Framework broadly covers the background information required for the document. However, it makes some assumptions about carers' lives that are not necessarily accurate for all carers. It is important in this introductory section to note that high quality, individualised care of the person with care needs from service providers with the input of the carer (where appropriate) is a support for the carer in its own right. If the person with care needs has a poor experience with services, this leads to greater stress for the family or friend carer.

General comments regarding this section are:

) Page 5, Paragraph 2: Suggest add 'Government Departments and Agencies' to community as to who the final Strategic Framework will guide.

) Page 6,

　o Paragraph 2: Suggest first dot point read, 'stay connected' with 'or re-connect' with and be involved in the community. Additionally, remove emotive language of 'people they love' from last dot point and substitute 'friends'.

　o Paragraph 3: Suggest that wording states that people who require support can remain in their own homes 'for as long as possible'. Despite carers best efforts,

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[20] Department of Local Government and Communities, 2015. Draft WA Carers Strategic Framework, page 6.

[21] http://www.carersaustralia.com.au/storage/Access%20Economics%20Report.pdf

[22] Department of Local Government and Communities, 2015. Draft WA Carers Strategic Framework, page 7.

sometimes the care needs become too great or the level of services required are not available or affordable to allow people to stay in their own homes.

    o   Last paragraph: It states that well planned support services are in place, however this is not the experience of many of the people who require them or their carers. Suggest to remove this statement all together or remove 'well planned'. Additionally, using language such as 'sacrifice' to describe the carers' role implies that they have to give something up. Although this may often be the case, it may reinforce a sense of helplessness rather than enabling carers to seek support. In the last sentence, it should also be noted that recognizing and supporting carers is also critical to the economic security of the community.

Legislative and Policy context

As alluded to in the introduction to this submission, ongoing care of Western Australians who are frail aged, with chronic health conditions, mental health issues (including alcohol and other drugs) and disability would not be possible without the workforce of unpaid family and friend carers. The economic contribution made by carers is substantial,[23] therefore the State Government should make it an economic priority that carers are identified, recognised and supported in their role.

There are issues that are particular to carers which need to be addressed such as transitioning in and out of a caring role which has impacts on the carers own health, mental health, wellbeing and their opportunities to participate in education and for financial security.

With regards to State Legislation, it has been raised by the Carers Representative Network at Carers WA that the Carers Recognition Act 2004 does not apply to private health and mental health services (unless funded by WA Health or the Disability Services Commission. Also the fact that services self-report against their compliance with the Carers Charter does not make Services fully accountable for.

Recommendation 13: *Table 1* to include relevant standards pertinent to carers, such as:

⟩   WA Carers Recognition Act 2004

⟩   National Standards for Disability Services

⟩   National Safety and Quality Health Service Standards

⟩   National Mental Health Standards 2010

⟩   Health and Disability Complaints Act 1995

⟩   UN Convention on the rights of people with disability

⟩   Mental Health Act 2014

⟩   Fair Work Act 2009 (2014) - referred to in Draft Document on Page 30.

Recommendation 14: *Table 1* should be made an appendix to de-clutter the document.

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[23] Access Economics. 2015. The Economic Value of Information Care in 2010. Deloitte and Carers Australia, Canberra.

United Nations Convention on the Rights of Persons with Disabilities – Social model of disability

The UN Convention on the Rights of Persons with Disabilities, to which Australia is a signatory, is consistent with a social model of disability and recognises the importance of access to social, cultural and economic environments in relation to health and wellbeing. The Convention also recognizes that having access to and exercising ones' human right, to fully participate in society, enhances an individual's sense of belonging. This concept is imperative to a person's recovery. In addition, the Convention recognizes the importance of enabling the family to gain assistance to allow them to aid the person with disabilities to fully assert such rights.

> *"Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities"* [24]

The assistance that carers and family members commonly need to fulfil this role involve, for example:

⟩ education and training around the condition of the person they care for and their subsequent needs and supports

⟩ facilitation of the involvement of carers, family members and friends in the development of treatment and care plans

⟩ facilitation of and enabling carers and family networks to be actively involved in the life of the person they care .

⟩ the development of models of practice that encourage the social, economic and cultural participation of individuals, which includes the inclusion and recognition of family and carers.

Recommendation 15: A social model of disability be included as a Guiding Principle for the Capabilities Framework, which is consistent with the UN Convention on the Rights of People with Disability.

Acknowledgment of current reforms which may impact on carers.

There are a number of reforms underway currently at a Commonwealth and State level which lend some uncertainty to the future funding of supports of carers. Please see a summary of reforms attached in Appendix B.

Carers WA believe that there needs to be an acknowledgement that the WA Carers Strategic Framework and its implementation will need to be considered in light of these reforms. The key reforms which may impact on funding for and how carer supports are delivered are as follows:

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[24] UN Convention on the Rights of the Person with Disabilities, Convention on the Rights of Persons with Disabilities and Optional Protocol, pg. 3.

The National Disability Insurance Scheme (NDIS)

Currently there are two trials operating of NDIS in WA, the National Disability Insurance Agency (NDIA) NDIS and the Disability Services (DSC) WA NDIS My Way. Funding that may have previously supported people with care needs are being absorbed into NDIS funding. Under NDIS funding is to be used to benefit the participant (the person with disability) and there are no direct carer supports included in this funding. Furthermore the funding under the NDIA Information, Linkages and Capacity building tier of supports is still being determined and is under consideration. This is unlikely to be implemented until 2017 in a phased approach. Again at this stage it appears that this funding will link carers to supports and build capacity but will not offer any funding unless it is based on a direct benefit to the participant.

Home and Community Care (HACC) Program

This funding will eventually be absorbed into NDIS for people under 65 with disability and the Commonwealth Home Support Program (CHSP). Already Carers WA has had issues raised from providers who were able to provide direct carer support under the National Carer Respite Program funding. This funding has now been absorbed into the Commonwealth Home Support Program which only funds services for consumers, not for their carers.

Consumer directed funding

In the emerging aged care and disability reforms, funding will sit with the consumer and be used for direct consumer supports or services. This reform to allow people choice and control is commended by Carers WA. However, under these reforms, Carers WA has a grave concern that if block funding for direct carer support services are not maintained outside or as part of this funding model, then carers may not receive the supports they need to maintain their caring role. This will not only having a detrimental effect on their own mental health and wellbeing but also risk leading to a situation where the carer is less able support the person/s with care needs. This can potentially lead to the person needing a higher level of formal/paid care supports or having to leave their family home to move into supported accommodation. Both of these situations will put a greater strain on Government budgets.

Recommendation 16: An additional sub section be added to Policy and Legislative Context Section to outline National Reforms which may impact on the WA Carers Strategic Framework. It should recognise that some reforms may impact negatively on the current level of carer supports. It should also note that the strategic approach should be to monitor the impact of these reforms on carers in WA.

3.3   Priority Areas

The format used within all the Priority Areas sections, with the quote as the first paragraph, is a pertinent way to introduce the themes. However, it may be beneficial to provide some further context relating the quote to the other content.

Unfortunately, the strategies for achieving the priority areas are not specific enough to explain what will be done and by whom. It is important that the relevant stakeholders are identified, so that there is accountability in achieving the outcomes.

Under 'What will help' sections, statements such as 'Identify, promote and/or implement new and [sic]innovate training packages' need to specify who will be responsible for the action and who the target audience is (i.e. carers or service providers or both?).

This should be applied to all strategy statements throughout the document.

For example, the following:

> *"Increase awareness of the carer role amongst the community, frontline service providers and people with caring responsibilities."* [25]

Could be replaced by:

> *"Quarterly information sessions delivered by LGAs in their regions for community, frontline service providers and people with caring responsibilities to increase their understanding of the caring role."*

The "What is already in place?" sections could be moved to an appendix to de-clutter the document. The National Carers Strategy includes items that are in place, but includes detail about the significance of investment and sufficient detail that explains what each item is delivering. A dot point list does not provide enough insight into current services for it to be meaningful.

Recommendation 17: Improve the specificity of strategies in each Priority Area.

Recommendation 18: Move the "What's already in place?" to an Appendix of the document.

Priority Area 1: Awareness, identification and recognition

This first Priority Area is very detailed, and appropriately so due to the depth of its content. Carer identification, awareness and recognition is the core of the carer legislation and is a continual battle for organisations like Carers WA to improve this in the community. The emphasis on diversity of people's backgrounds is commendable.

Am I a carer?

The explanation of hidden carers contains the majority of reasons why carers could be hidden. The term carer can often be used by people when referring to 'paid support workers'. In addition, through the survey conducted by Carers WA in preparation of the Strategic Framework, a number of carers did not see the value in self-identifying and also felt it did not need to be public knowledge. For example,

> *"Family and friends already know that I am a carer for my husband. Is it necessary for the public to know that I'm a carer?"*

> *"Being a carer doesn't give us any special privileges or leeway…"* [26]

Recommendation 19: Include three more reasons that carers are hidden, i.e. 1) perceived lack of benefit to self-identify; 2) the desire for privacy; and 3) confusion based on societal use of the term 'carer' to describe someone undertaking the role in a paid capacity.

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[25] Department of Local Government and Communities, 2015. Draft WA Carers Strategic Framework, page 16.

[26] Response from two carers in response to Carers WA Survey, question 3.

Carers diversity

The current version of the Strategic Framework, provides a comprehensive explanation of diversity within the caring role and the varying impacts across those diversities. However, it is not only the person's background that highlights the diverse situations that carers experience. The care needs that people experience are very different as well. The role of carers of people with mental health issues, alcohol or other drug issues, disability, frail aged or chronic conditions have similarities, but also distinct differences.

Recommendation 20: Include 'care needs' as a type of diversity for carers.

The *Carers Diversity* section requires some additional work to specify and fully explain the argument. In particular, the use of the word "these" is not clear to what is being referred, e.g. "these backgrounds", "these carers" and "these [sic] on grounds"[27].

Recommendation 21: Specify and clarify the language used in the *Carers Diversity* section.

Recommendation 22: In Table 2, Page 16 of the document the following additional strategies are recommended for consideration:

⟩ Developing Carer Resources, such as a Carer Concession Card.

⟩ Utilising social media, public media and appropriate services advertising to promote the positive and rewarding side of caring. See Appendix A for specific strategies.

⟩ Develop a short questionnaire to be distributed publicly for carers to assess themselves as being in a caring role.

⟩ Expansion of the strategy "Public awareness campaigns that promote the carer role and responsibilities"[28] to include the difference between an unpaid carer and someone working in a paid capacity.

⟩ Expansion of the strategy "Education and training for health professionals"[29] to include undergraduate students and working professionals in relation to all caring related sectors, such as mental health, alcohol and other drugs, aged care and disability. A further expansion of this could also include education and training for any professional who is likely to be in a role which will identify and support carers, this would include primary and secondary teachers who are ideally placed to identify, support and refer Young Carers.

Priority Area 2: Respected partners in care

An important benefit of including carers in the design and delivery of services, is the delivering of a more effective service. It can be more cost effective to ensure that the person with care needs receives appropriate support from their carer, and will require fewer or less expensive service support. As an example, a carer should be communicated with appropriately regarding medication management and falls prevention when discharging someone from a tertiary hospital. If this occurs, then the likelihood of readmission to hospital is less and the person with care needs can potentially be managed by the carer and their General Practitioner.

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[27] Department of Local Government and Communities, 2015. Draft WA Carers Strategic Framework, page 13.

[28] Department of Local Government and Communities, 2015. Draft WA Carers Strategic Framework, page 16.

[29] Ibid.

However, if this does not occur, then the likelihood of readmission[30] to the emergency department is greater, which is a much higher cost to the government.

Recommendation 23: Include an argument for the partnership between service providers and carers that demonstrates the financial benefit to providers (e.g. Department of Health, aged care facilities, disability providers etc.)

In referencing the Western Australian Carers Charter, it would be beneficial to include all four items from the charter. There doesn't appear to be justification for the removal of the following two items:

⟩ Carers must be treated with dignity and respect.

⟩ Complaints made by carers in relation to services that impact on them and their role must be given due attention and consideration.

Recommendation 24: Include the whole Carers Charter in Priority Area 2.

Recommendation 25: In Table 5, Page 20 of the document the following additional strategies are recommended for consideration:

⟩ Review the Carers Recognition Act to apply across all government agencies. Of particular note is the need for the legislation to include Private Hospitals and ensure that the treatment of carers in these institutions are in line with the legislation.[31]

⟩ Government staff to more actively approach carers and family members to understand their caring roles. For example:

    o   Carer related topics to be included in tertiary education programs

    o   Health and other relevant IT systems e.g. GP's, LGA's, link to referral of carer to Carers WA for follow up when identified.

Recommendation 26: In Table 6, Page 21 of the document the following additional strategies are recommended for consideration:

⟩ The Department to coordinate the implementation of the Strategic Framework, working with carers and government agencies to develop action plans and templates for carer identification and recognition.

⟩ It is recommended that a framework is used to assist with the strategies that define the public's role in any community engagement program, such as the IAP2 Spectrum[32].

Priority Area 3: Supporting carers

Information and training

This section broadly covers the range of supports required by carers. Carers receive information from a number of Government Departments and NGO's, it should be

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[30] Tao, Hong et. al. (2012). *Advances in Nursing Science.* The influence of Social Environmental Factors on Rehospitalisation among Patients Receiving Home Health Care Services. Vol. 35, No. 4, pp. 346-358. Wolters Kluwer Health, Lippincott Williams & Wilkins

[31] Recommendation taken from minutes of the *Carer Participation in Health Forum*, in response to specific feedback from membership on 18 November 2015.

[32] https://www.iap2.org.au/resources/iap2s-public-participation-spectrum.

acknowledged they may need information, training and support specific to the condition of the person they care for and tailored to the carer depending on their age e.g. Young Carers, older carers, cultural background, condition of the person they care for or depending on the length of time they have been in a caring role.

A large study in the United States of America showed that 'Family caregivers providing substantial assistance with health care experience significant emotional difficulty and role-related effects, yet only one-quarter use supportive services'. [33]

> *"Carers need information on when to recognise their own health is at risk due to the caring role[34]."*

Previous research suggests that male carers are less likely to access support services, than female carers.[35] [36] A review of barriers and facilitators for male carers in accessing formal and informal support found that research into male carers' experiences in accessing support remains underdeveloped. Research that distinguishes between, for example, the experiences of spouses and sons and with direct comparisons between male and female carers is needed. Whether gender specific services would benefit male carers remains undetermined. [37]

The main concerns of older carers is what will happen when they are not able to provide care anymore due to health issues or when they pass away. Older carers can benefit from planning for the future in the case of unexpected events. A survey conducted by Anglicare showed that a lack of assistance and affordability was a major factor contributing to carers not having a transition plan.[38]

> *'Some supports involve so much administrative burden and time for the carer to organise they are not thought to be worth it.[39]'*

Research conducted by the Southern Cross University on providing end of life care highlights the reluctance of LGBTIQ carers to access appropriate health care support services. This research highlighted that this reluctance was due to the additional burden of stigma and the fear of discrimination and violence, which may contribute to a lack of identification of LGBTIQ carers by service providers[40]. LGBTIQ carers may also feel uncomfortable disclosing their sexuality or gender identity, which may restrain their use of services[41]. The results of a survey

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[33] JAMA Intern Med. Doi10.1001/jamainternmed.20157664 published online February 15, 2016

[34] 2016 Carers WA - WA Carer Strategic Framework Carer Survey

[35] Baker, K.L. & Robertson, N. (2008). Coping with caring for someone with dementia: reviewing the literature about men, Aging Mental Health, 12, 413–422.

[36] Cahill, S. (2000). Elderly husbands caring at home for wives diagnosed with Alzheimer's disease: are male caregivers really different*, Aust. J. Soc.*, 35, 53–72.

[37] Greenwood, N. & Smith, R. (2015). Barriers and facilitators for male carers in accessing formal and informal support: A systematic review, Maturitas.

[38] Bellamy, J., Paleologos, Z., Kemp, B, Carter, S. & King, S. (2014). Caring into Old Age: The wellbeing and support needs of parent carers of people with disabilities. Anglicare, Sydney.

[40] Carers Queensland (2012). Submission to the National LGBTI Health Alliance – National LGBTI Ageing and Aged Care Strategy. http://carersqld.asn.au/wp-content/uploads/Carers-Queensland-Submission-to-National-LGBTI-Alliance.pdf

[41] LGBTI Foundation UK (2015). Carers. Manchester, UK. http://lgbt.foundation/information-advice/Carers/

undertaken by Carers Victoria's in 2015 on Young LGBTI, showed that one third of the Young LGBTIQ Carers surveyed said their sexuality, gender identity and/or intersex status affects how easy it is for them to ask for help and/or who they ask[42].

Carers of people with a mental illness can feel overwhelmed by their caring role[43]. This can result in carers having their own long-term mental health problems, especially depression, anxiety and stress are common issues of carers supporting someone with mental health issues[44]. SANE (2007) research indicated that up to 40% of carers experience mental health issues themselves as a result of caring[45].

Recommendation 27: Department for Local Government and Communities partner with Carers WA to fund and develop a range of information resources suitable for different carer backgrounds and caring situations. These can be made available in print form and online.

Recommendation 28: The needs of LGBTIQ carers need to be considered as distinct individuals and the diversity within groups need to be taken into account.

Recommendation 29: Research is carried out into what supports are effective for male carers.

Recommendation 30: Programs that assist older carers to build skills, establish social contact and fund legal costs, in association with planning for the future.

Recommendation 31: Employment of Indigenous staff within mainstream services, who have the skills and knowledge to support carers, may be beneficial for the Indigenous community as well to promote culturally safe service delivery.

Recommendation 32: Carers of people with mental health issues have information and support available to them that addresses their specific needs.

Good Health and wellbeing

Carers cite not having time to care for themselves and having to care often 24/7 for one or multiple people taking a toll on their own physical, mental and emotional wellbeing.

Respite was the most commented on need in the Carers WA survey in relation to the development of a WA Carer Strategic Framework; 30% of respondents made comments regarding respite. The framework needs to emphasise the importance of having a high standard and quality of respite available. This receives a brief mention, but if respite services are not of a high quality and relationship based then it is not effective. Carers having a negative experience of respite are less likely to access it again which will eventually lead to an increase in carer strain. Gaps in funded respite also need to be acknowledged in relation to carers of people with mental health issues, children with disability and challenging behaviours and in regional and remote areas of WA.

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[42] Carers Victoria (2015). Young, queer, and caring survey results, June 2015. Melbourne http://www.carersvictoria.org.au/how-we-help/LGTBI-carers/young-queer-and-caring-survey-results-june-2015/

[43] Hughes, J. (2009). Caring and Mental Health: No Small Issue. *Health Voices, Journal of the Consumers Health Forum of Australia. 5,* 1-2.

[44] Ibid.

[45] SANE Australia. (2007). Research Bulletin: Family carers and mental illness. Sane Research, 1-2.

> *"I want the option for the whole family to take a holiday and access to respite in places where we want to holiday"* [46]

> *"I suffer [from] chronic neck pain and anxiety. I feel overwhelmed most of the time. I'm on medication to help me cope."* [47]

Recommendation 33: The heading of table 8 be changed to 'Actions to support carers to be well' (rather than remain well) as carers have the lowest level of wellbeing of any other collective group in society[48] and may need to be supported to regain a higher level of wellbeing than they are currently experiencing.

Recommended additional strategies

Recommendation 34: In Table 7, Page 24 of the document the following additional strategies are recommended for consideration:

⟩ All services should have systems in place to provide information to carers which is tailored to their needs.

⟩ In the UK carers have the right to take part in a carer assessment via their local council. This could be delivered by the network of Local Government Authorities or in partnership with local providers in WA. [49] Following the assessment a care and support plan is developed for the carer. A similar model could be funded to assist to 'join up services'.

⟩ Workshops for carers need to be held outside of working hours, in the evenings and weekends and/or online to allow maximum accessibility.

⟩ Suggest to not refer to specific service providers, rather refer to a central information hub or directory where these services can be accessed.

⟩ Information provided needs to reflect the carers' journey and be provided step by step.

Recommendation 35: In Table 8, Page 25 of the document the following additional strategies are recommended for consideration:

⟩ Supporting carers to identify what life opportunities they wish to pursue and how to go about sourcing it once they have respite / time to switch the focus to themselves or when their caring demands reduce, i.e. Returning to work / study / up skilling / readiness and confidence to contribute to society outside the caring role.

⟩ Services implement systems where they proactively and regularly reach out to carers (who request this service) and provide regular follow up as to their wellbeing.

⟩ There needs to be campaigns to let carers know that it is important to seek help for their own wellbeing.

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[46] Ibid

[47] Ibid

[48] Cummins, Robert; Hughes, Joan; Tomyn, Adrian; Gibson, Adele; Woerner, Jacqueline and Lai, Lufanna (2007). Wellbeing of Australians: Carer health and wellbeing, Deakin University, Geelong, Vic.

[49] https://www.carers.oeg/carers-assessment

〕 There needs to be adequate funding for respite that is flexible and suitable to the person with care needs and the carer. For example, on demand, after hours or for hours through to weeks of length.

〕 Family friendly respite, e.g. respite provided for the family to holiday together with the person with care needs.

〕 There needs to be additional flexible strategies to support carers when the person they care for does not consent to accessing supports.

〕 Carers report that respite services are not available to cater for people with challenging behaviours. More services need to be made available who are able to care for people with challenging behaviours to give carers some time out.

〕 Respite available that is culturally appropriate or appropriate to specific carer needs e.g. gender or other preferences for support workers.

〕 Greater provision of 'in-home' respite

〕 Services to provide consistent staff to provide services - a constant change of support or other workers is a reason that carers are reluctant to accept support.

〕 Equipment to be suitable for the person with care needs but also takes into account the needs of the carer.

〕 Provision of adequately trained staff and facilities to provide respite for people with high care needs e.g. Tracheostomy, PEG tube feeding, Challenging behaviours.

Priority Area 4: Participation in education and employment

This section broadly outlines the challenges carers face in engaging in education and meaningful employment. Young Carers in Schools Program (DLGC/Carers WA) is listed under 'What's already in place' however this information is inaccurate as the program is no longer funded by the Department.

Recommended additional strategies

Recommendation 36: In Table 11, Page 29 of the document the following additional strategies are recommended for consideration:

〕 Transition plans to assist young carers move from high school into further education or employment alongside planning prospects for person with disability.

〕 Education to be available to carers on managing care e.g. medications, manual handling and condition of the person with care need e.g. managing challenging behaviour.

〕 Carers require education on self-care and how to recognise when they need a break.

Recommendation 37: In Table 12, Page 30 of the document the following additional strategies are recommended for consideration:

〕 Funded 'Return to Work Programs for Carers

〕 Service for working carers where care recipient is remotely monitored during work hours. Fund pilot service to introduce and test monitoring service

⟩ Carers are supported to have the same opportunities for career progression/promotion as other employees.

Recommendation 38: In Table 13, Page 30 of the document the following additional strategies are recommended for consideration:

⟩ Recommend that undergraduate students of courses in Aged Care, Health, Mental Health, Alcohol and Other Drug Services and Disability receive education in relation to carer recognition in their curriculum.

⟩ Greater awareness of the specific issues in relation to Young Carers in the workplace, often not recognised as possibly caring for a parent or sibling when needing to take personal leave.

⟩ Staff within Disability, Mental Health, Aged Care, Alcohol and Other Drug and Health Services to receive education regarding carer recognition during orientation and induction programs.

⟩ Creation of resources for Employers and Educators to be 'Carer Friendly'. For example Carers Australia 'Work and Care' resources[50].

Priority Area 5: Data and evidence

An additional piece of evidence that is in place is a report produced every five years by Deloitte; Access Economics. The report is titled '*The economic value of informal care in Australia in 2015'*,[51] as noted on pg. 6 of the Strategic Framework.

The Australian Institute of health and Welfare is another worthwhile source of information and data related to carers. [52] More specifically, there was a '*Carers National Data Repository scoping study'* that could be revisited.[53]

Recommendation 39: In Table 14, Page 31 of the document the following additional strategies are recommended for consideration:

⟩ Improving the questions included in the census to better reflect the recognised definition of carer.

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[50] http://www.carersaustralia.com.au/work-and-care/work-and-care-employers/

[51] http://www.carersaustralia.com.au/storage/Access%20Economics%20Report.pdf

[52] http://www.aihw.gov.au/

[53] http://www.aihw.gov.au/publication-detail/?id=6442468274

4. Appendix A: Carers WA survey results

4.1 Questions

1. What supports/services for carers that currently exist are most helpful to you in balancing your caring role with other priorities (work, education, family, relationships, self-care etc.)?

2. What gaps in supports/services for carers currently exist?

3. What do you think should be the top 3 priorities of a Government Strategy for supporting carers in WA?

4. How can the recognition of carers (within the workplace, schools, health and other services, the wider community etc.) be improved?

5. What do you think should be the top 3 priorities of a Government Strategy for supporting carers in WA?

6. Do you have any other comments?

4.2 Respondents

⟩ Online survey respondents – 191 Carers

⟩ Face to face groups:

  o   Vietnamese Linking Together Group – 12 Carers

  o   Beeliar Wellbeing workshop – 8 Carers

  o   Young Carer Advisory Group – 8 Young Carers

  o   Ellenbrook Wellbeing Workshop – 11 Carers

Total number of survey respondents = 230 Carers.

4.3   Key findings

Table 1: Themes and recommendations from survey of carers completed in September 2015

Theme	Description	Recommendation
1. Respite	The need for regular, affordable, accessible, quality respite. Lack of respite, funding for respite or suitable respite	More funding needed for respite (particularly in regional areas) Need qualified staff to provide respite Need increased support for children with disability for carers to have a break Quality respite with the person with care needs is well received by carers Need for more in home respite Discount for entertainment venues Respite options needed for young adults with autism Need respite available out of working hours for carers who work. Most services aimed at elderly, need to meet the requirements of younger people who require care. Centre based day care Want to be able to go away for a weekend Short break funding Carer using a consumer directed respite package – has a wide application of funds There is a need for couples respite (not just mums or dads) When people with care needs are engaged in activities which kept them involved in the community, it was of benefit to the carer. More Respite for recipients which builds on their life skills and at the same time gives the carer a break. "I want the option for the whole family to take a holiday and access to respite in places where we want to holiday." Need affordable respite for 4-6 hours, over a weekend, 3-4 nights, a full day or a week. Lack of services who can provide respite for people with challenging behaviors - carers are left to cope with no break

		Increase respite accommodation
		Accommodation for carers visiting city from regions for family member to get city based medical care
		Appropriate respite services available and suitable for individual circumstances
		Additional training for staff to ensure they are aware of the carer's condition when providing a service to the care recipient
		Promoting health and wellbeing of carers and encouraging self-care
		"Many comments that there is not enough respite available/funded"
2. Employment	Impact of caring role in being in work or re-entering the workforce:) Lack of flexibility at work or ability/capacity to re-enter work.) Positives of being in work.) Carer Payment versus having a wage.) Improved training of staff in health, disability, mental health and aged care on the importance of carers. Employers encouraged to provide workers who also care with flexible conditions.	Flexible working hours Paid personal leave for caring Work opportunities for the person with disability which in turn benefits the carer (PWD frustrated) Being able to work I have been overlooked for work opportunities An understanding workplace. Should be paid a wage for caring role, not be on a pension - saving the government billions of dollars Penalised for working by losing pension if work too many hours - work is a form of respite for me and 'me' time. There is no requirement for the employer to be flexible. There is no support for people who are working and caring, as they have to pay full price for everything they get no breaks. "I dropped to part time work to be a carer and do party plan work as well to enable me to work flexible hours. I worry about money for my retirement." "Due to my son's challenging behaviors he has been suspended from most services which would give me respite. I have had to quit working many times to care for him. I have very little superannuation or savings." "I need assistance to re-skill and get meaningful part-time and flexible paid work which fits in with caring responsibilities."

		Carers need support early in the caring role so they can maintain their position in the workforce rather than having to leave it. They should not have to pay for re-education to reenter the workforce.
		Should be able to receive a Carers Newstart pension until able to reenter the workforce.
		There needs to be a pathway and support for carers to eventually return to the workforce once their caring role ends.
		Lack of awareness of Young Carers in the workplace
		Less likely to be an understanding of a young carer needing time off work to care for a parent vs. a parent needing to carer for a child for example.
		Inclusion of caring in orientation to the workplace in health, disability, mental health and aged care
		Workplaces allowing more flexibility for staff to make up time when they need to attend medical appointments during normal work hours
		Mandatory leave entitlements of carers leave, in addition to personal leave
		Service for working carers where care recipient is monitored during work hours
		<u>Recommended HR Policies</u>
		Inclusion of carer recognition in orientation to the workplace in health, disability, mental health and aged care
		Workplaces allowing more flexibility for staff to make up time when they need to attend medical appointments during normal work hours
		Mandatory leave entitlements of carers leave, in addition to personal leave
		Government campaign and lobbying of employers to increase flexible work practices for carers
3. Practical Support	The need for practical support to relieve the carer	Less support supplied since moving from HACC to a package of care, requests not fulfilled
		Domestic support very helpful
		Gender specific personal care
		Need a higher level of 'package' hours to prevent the person needing to go into care
		Transport needed in rural areas

		I rely on friends for transport or have to pay myself (transport no longer covered under a home care package vs. HACC)
		Some supports involve so much administrative burden and time for the carer to organise they are not thought to be worth it
		Increased level of support being available if the carer has their own health issues
		Carer Smartrider is a good initiative
		Inappropriate equipment which may be suitable for person for care needs but not for the carer
		Service for working carers where care recipient is remotely monitored during work hours. Fund pilot service to introduce and test monitoring service
		Need taxi and transport options for taking person with care needs to hospital - parking vouchers
		Meals provided are often unhealthy/unappetising
		Multiple issues listed by YC's in relation to Medication information and lack of information from Hospitals and Doctors
		A number of services and service providers were listed as being helpful including Carers WA.
4. Carers not accessing supports	Reasons why carers are not accessing support	Not aware of available supports
		Some didn't feel they need any support
		Person they care for refuses to accept supports
		A case manager who can come to home and work up an individual plan with Carers
		Developing a checklist of supports available vs. what is needed
		Feel it is ultimately up to me and I cannot rely on anyone
		No access to services as I work full time- need after hours supports
		No respite options that are suitable.
		General lack of knowledge of what is available and where to find it.
5. Peer Support	What peer support is useful and what is needed.	Lack of opportunities for group outings
		Monthly carer support meetings/sharing a meal
		Swapping information

		Siblings/Young carer events
		Programs facilitated by peers
		Online support groups – Facebook
		Groups need to be appropriate to the carers experience
		Online forums for people who cannot access social support during work hours.
		Fund carer peer program to train and support peer support mentors
6. Informal Support	The benefit of having the support of family and close friends	Support of family and friends/relationships
		More isolation in regional areas
		Friends and neighbours pitching in with practical tasks
		A number of respondents listed NOT having any family or friends to assist as being an issue – recommend ways to build up other informal networks in the community
7. Emotional/Mental/Physical Health-Support & Wellbeing	How people felt their emotional and other wellbeing was supported Services and supports designed to improve health and well-being of carers	GP useful in caring for own health and referral to counselling/mental health plan
		Need more support for mental and emotional problems as a result of the caring role
		Counselling
		Phone support
		Self-care
		Advocacy
		Hospital Social Workers
		Acknowledgement of my caring role/ Recognition and respect of my caring role.
		Better self-care support for carers needed particularly mental health.
		Several carers mentioned that a follow up phone call service to see how they are going would be appreciated. Can be hard for the carer to make follow up calls for support.
		More education required on how to manage life's priorities when all of your family has a mental illness
		Psychological skills needed in managing caring for someone who is in pain and unwell.
		Carers may have their own health issues which make it difficult to care for others
		"I care for two high needs people and have severe depression myself but only get 4 hours of support per week."

		Physical stress of caring coupled with mental health needs need to be addressed.
		"We need a break as 24/7 care is demanding and tiring and causing our health to suffer also."
		No time for self-care
		Carers should still receive support even if the person they care for is in hospital
		If the carer gets sick they have to try to recover whilst still caring.
		"My dad has dementia and as his cleanliness (incontinence) becomes an issue he cannot attend day centers which puts more pressure on me."
		Carers need information on when to recognise their own health is at risk due to the caring role.
		"I suffer chronic neck pain and anxiety. I feel overwhelmed most of the time. I'm on medication to help me cope."
8.Financial Support	The provision of adequate finances to maintain caring role	Emergency funding for situations that arise for the person with disability so carer not having to use their own funds
		Need consistent information from Centrelink
		Pay for carer to have a membership or attend events with person with disability *(perhaps not aware of companion card)*
		CAP funding *(this will get absorbed into NDIS)*
		Shared management of funding with Service Provider
		People are needing to work at the expense of caring as they cannot afford to live on a parenting or carer's payment. This causes increased stress for working carers when the person they care for has high care needs.
		Funding received to allow respite options was the most appreciated use.
		More concessions required for carers e.g. parking
		Difficult to get credit loans, rentals as the caring role not recognised as a reason to not be working.
		Respite options too costly.
		It gets harder each year to make ends meet.
		Need to have a wage not a pension
		Retain, protect existing and increase carers payment and allowance

		Government offer tax breaks, in kind supports, financial support for training to aid employment and income earning of carers, travel and fuel discounts
		Losing Carers Benefit when person in hospital '63'day rule does not recognise the care still provided whilst someone is in hospital
		YC's find that it is more difficult to go through the Centrelink process due to their young age.
		YC's find it difficult to get the Carers Payment /Allowance due to the hours they are at school even though providing care overnight and have to take calls during the day whilst at school
9. Information/Education	Accessing information	Ways information is received
		Workshops
		From service providers
		GP
		Needs/Recommendations
		Availability of an empathetic telephone service for carers to be able to access
		Transition plans from high school and planning prospects for person with disability
		Information on mental illness
		Assistance in dealing with government agencies from carer support services
		Carers require more information on managing care e.g. medications
		"Workshops rarely at a time when I can attend them."
		How to manage when the person you care for refuses supports
		Carers WA workshops are helpful
		Foodcents workshops (via Carers WA) helpful
		Information for carers should be step by step and describe what you need to know from the beginning of the carers journey
		Information should be freely given
10. Service Providers	Providers listed as being useful	A number of service providers were listed as being useful mostly not for profits, hospitals and GP's

		There was an issue with Service Providers not having enough staff to respond to the person with care needs which caused preventable stress to the carer
11. Systems	Difficulty in navigating services and supports Need for flexibility of and coordination between services	DVA and Centrelink using different calendar years, resulted in financial disadvantage Have to go to too many places to organise services Mental health services, long waiting times/callbacks not made Lack of consistent staff at services - need to repeat story Lengthy paperwork and information required to meet eligibility requirements Lack of coordination between services Confusion as to what services are available - need assistance to navigate them. There are not enough supports in the system or funding to provide high level of care support in the home, which means that people need to go into supported accommodation, despite the carer wanting to keep them at home. Lack of after hospital care provision (e.g. outpatient clinic support) No consistency in standards of service delivery of NGO's Lack of training of support staff. Would like a case worker to coordinate supports Lack of services in outer metro, rural and regional areas Lack of supports for families with children with disability Frequent changes to funding so services not able to be continued. General lack of flexibility in services to provide after working hours supports. "There is no room for unexpected activity, if I receive an invitation at short notice I cannot go." Little support over weekends and public holidays Need 'on-demand' services. Fund organisations across all regions of WA to setup social support groups Ensure funding that is being redirected away from Carers at a national level (NDIS, Commonwealth Home Support Program) is compensated by the state Continue to fund direct carer supports

		Lack of follow up/miscommunication/lack of response from Service Providers
		Needs to be improved systems to reduce waiting times for appointments, particularly in hospitals.
		Lack of disability access
		YC's feel there is more money allocated to Mental Health supports and not enough in disability.
		Needs to be better referral points for YC's
		Needs to be a case management approach in Education.
		Needs to be earlier diagnosis of conditions so that supports can be put into place early
		Service providers not aware of their own services or other services e.g. NDIS.
		Service providers need training in basic customer service skills.
		Service Providers need to 'reach out' to carers (i.e. identify them and provide them with information)
12. Carer Recognition, Identification and Inclusion	Lack of recognition of the carers role Identification of carers by self and others Carers being involved in planning, development, delivery and evaluation of services. Carers being treated as 'Partners in Care'	Issues and Recommendations More widespread use of the term carer across government agencies Recognition of the particular difficulties of sole parent carers Needs to be celebration of carers at particular times of year e.g. Christmas Lack of being listened to, constantly having to prove your caring role Lack of recognition of mental health caring by Centrelink There is a lack of dissemination of information about the person being cared for from Doctors to the carer More recognition of the role, contribution and value of carers There is lack of recognition of carers if they are not family members Lack of recognition of carers by staff in residential care Lack of understanding of the carer role by Centrelink staff - need to have training and employ more carer liaison staff Needs to be more recognition of the carer as having valuable knowledge about the person with care needs

Carers often excluded from communication by Mental Health and AOD services; no pro-active outreach to carers by services

Need greater community awareness of range of carer supports and that it is OK for carers to seek support.

Developing a badge for carers that identifies them in government services

Develop a "Carer" concession card

Carer awareness policies in the workplace

Advertising in GP surgery waiting rooms

Presentations to children in schools

Award a carer as "Australian of the Year"

Statewide TV, radio, magazines and newspaper (state and local) advertising campaign

Advertising in public places and public transport

More information and education sessions of people in the community, workplaces and schools

Books and stories demonstrating positive experiences of people in a caring role

Further education of government staff to increase their awareness of support networks of the person with care needs

Implementation of carer related topics included in tertiary education programs

Health IT systems link to referral of carer to Carers WA for follow up when identified

Development of programs to recruit and encourage carers to be involved in planning of services across health, disability, mental health and aged care

Encouragement of workplaces, schools and community groups to have carers talk about their role and its importance for the community

Suggest promotions in shopping centres, hospitals, senior centres, libraries

GP's should encourage people to identify as carers

A carers card would assist people to be recognised

Improved referral from social workers

Lack of carer recognition from Mental Health Services

Needs to be better recognition of the care that is provided and money it saves the economy.

		Lack of community awareness of disability - need to increase respect
		Lack of awareness of YC's in Education - Teachers need to recognise and identify YCs. Dept. of Education needs to support this need.
		GP's and hospitals do not listen to young carers
		YC's can be seen as anti-social due to their limited availability.
		More funding to promote YC's via TV, Festivals, YC specific festival, School days/open days.
		Services need education re carer recognition
		Needs to be systems in place e.g. IT or other documentation for Service Providers/GPs to identify carers and make referrals.
		Self-Identification:
		Develop a short questionnaire to be handed out publically, e.g. National Carers Week, that also highlights the supports and services available for carers
		Expand the census questions to ask people practical questions about a caring role There is confusion between unpaid, family carer and a paid support worker. Removal of the term carer may help carers to self-identify
		Statewide TV, radio, magazines and newspaper (state and local) advertising campaign
		Advertising in public places and public transport
		There is confusion between unpaid, family carer and a paid support worker. Removal of the term carer may help carers to self-identify. Develop consistent language across sectors for paid support workers Rename carers as "personal support person" or "family and friend support".
		There is the need to build respect for the young carer role to help them to self-identify.
13. Culturally and Linguistically Diverse (CaLD) Carers	Responses from CaLD Carers specific to their needs	Carers do not access services due to language barriers
		Want CaLD specific resources (information) and education - culturally specific and including interpreter services
		More services needed suitable for the CaLD
		community/carers
		CaLD carers feel that they are ignored.

		Things that work well - Respite, HACC, Aged/Day services, School Holiday programs, LACs (when do job), Monthly linking together group, guest speakers, availability of interpreters
		Positive - having a regular facilitator for the social support group
14. Young Carers	Reponses from Young Carers(YC)specific to their needs	Helpful supports specific to YC's include, Camps, Soroptimist grant, YC Bursary, Tutoring, Food vouchers
		Gaps - lack of central referral point for services, gardening.
15. Advocacy	Suggestions	There was seen to be a need of Young Carers to have a case manager or someone who could add weight to the YC's where YC's may not be taken seriously (advocacy)
		More advocacy required in Hospitals
		Centrelink needs a separate section just for carers