The *Carers Recognition Act 2005* – South Australia Review of Act – 2023/2024 Report – Proposals for legislative change

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1 Preliminary

Each morning in this country more than 2.6 million people wake up and their first thought is for the needs of someone else. These people are Australia's carers. They are family members, friends, partners, parents, children, or neighbours who care for a loved one with disability, medical condition, mental illness or who is frail.¹

1.1 Introduction and terms of reference

The *Carers Recognition Act 2005* (the **Act**) relates to exceptionally important people in our South Australian community – carers.

The Act is important because it gives statutory recognition to carers and provides various mechanisms designed to promote the interests of carers.

This is the second review of the Act. The first review was initiated 5 years after the commencement of the Act and primarily related to the operation and effectiveness of the Act.²

The State Government engaged Richard Dennis AM PSM³ to undertake this second review.

Essentially, the purpose of the review has been to consider the operation and effectiveness of the Act in recognising carers.

The terms of reference for this review are as follows:

- (a) how well is the operation of the Act achieving or supporting the objects of the Act, and any recommended amendments;
- (b) the extent to which the *Carers Charter* is recognised and applied for the purposes of the Act and whether amendments should be made to the Charter to improve its effectiveness under the Act;
- (c) whether additional kinds of carers should be recognised under the Act;
- (d) the extent to which additional steps could be taken to support and improve the recognition of carers in the community and in interacting with the State;
- (e) consideration of amendments should be made to any other State Act to give express recognition to carers; and

¹ <u>https://www.carersaustralia.com.au/wp-content/uploads/2020/08/2011-National-Carer-Strategy.pdf</u>. This is a quote from a document in 2011 and while the carers in Australia would now be greater in number, the significance of the message remains the same.

² See section 9 of the Act. The first review was carried out in 2010 - 2011

³ Former South Australian Parliamentary Counsel (2006 – 2015).

(f) the extent to which the recommendations from the 2011 review have been adopted and been effective.

The reviewer was particularly interested to identify:

- (a) what is working well; and
- (b) what is not working as well as it should; and
- (c) what can be done to improve the effectiveness of the Act.

It is noted that the focus of the Act is the recognition of carers and the role that they play in the community. The Act does not make provision in relation to the actual services or funding that are provided to the people that carers support. This means that the focus of the review has been to find out what can be done to give better recognition to the role of carers as this relates to Government departments and agencies and does not relate to services or funding.

It is also noted that this report focuses on the recommendations that propose changes to legislation.

1.2 Process

The review has mainly been conducted by the reviewer -

- (a) meeting with key people interested or involved in the operation or administration of the Act;
- (b) seeking responses to an issues paper prepared by the reviewer;
- (c) seeking submissions, and the completion of a survey, via YourSAy, and promoting the review via social media and a webpage on the Inclusive SA website;
- (d) conducting a public forum and a stakeholder workshop;
- (e) conducting his own research and analysis of the Act and other Acts and resources considered relevant to carer recognition;
- (f) considering legislation in other jurisdictions.

The reviewer expresses his sincere appreciation to each person who made time to meet with him, to make a submission for the purposes of the review, especially in response to the issues paper that was prepared for the purposes of the review or in response to the survey, and/or to attend the public forum or the stakeholder workshop. There is no doubt that the Act is an important piece of the legislation given the significance of carers to our community and there are some wonderful, dedicated people who have an interest in this Act and who were willing to participate in the review.

This report does not make reference to all matters that were raised with the reviewer (and some of them should be kept confidential), or to some of the recommendations or changes proposed during discussions, the forum or workshop, via YourSAy and the survey, or in submissions. In general, a decision not to adopt a suggestion or recommendation has been

based on an assessment that a particular change to the Act was not required, was not advisable in the circumstances, or would not be appropriate given the legislative scheme or the objects underpinning the Act. However, as indicated above, each suggestion or recommendation has been very much appreciated and the reviewer trusts that this report results in significant improvements in connection with this important piece of legislation.

It is also noted that a separate report on the consultation and feedback received during the course of the review has also been prepared as part of the processes associated with the review. This separate report includes a list of individuals and organisations who provided submissions, or who were specifically consulted, for the purposes of the review, and a summary of the feedback received via YourSAy.

It is also important to note that this review was being conducted at the same time as the *Inquiry into the recognition of unpaid carers* was being undertaken by the House of Representatives Standing Committee on Social Policy and Legal Affairs, and that this report was very close to being finalised when the report of that Inquiry was released. This timing has meant that the reviewer has only had a very limited opportunity to consider the report and recommendations of that Inquiry, and that it has not been possible to give extensive consideration to how the recommendations of that Inquiry might "line-up" with the recommendations from this review. This is something that will need to be considered by DHS in due course.

1.3 Carers in South Australia

1.3.1 Importance of carers

The importance of carers in the South Australian community is self-evident.

Information published by *Carers Australia* indicates that there are over 2.65 million carers across Australia⁴ (and the Carers SA website now refers to over 2.7 million carers in Australia)⁵, that carers make up nearly 11% of Australia's population⁶, that around 861 000 carers are primary carers, and that the weekly medium income of primary carers aged 15 – 64 is \$800, compared to non-carers who receive a median weekly income of \$997⁷. A 2018 survey of Disability, Ageing and Carers estimated that 181,300 South Australians are carers, and it could be expected that the number is much higher now.

The information also indicates that up to 7 out of 10 carers are women (and this would contribute to women falling behind in such things as career opportunities and superannuation entitlements), and that one-third of primary carers provide 40 hours or more of unpaid care per

⁴ Drawn from the 2018 *Survey of Disability, Ageing and Carers.*

⁵ See https://www,carerssa.com.au.

⁶ Also drawn from the *Survey of Disability, Ageing and Carers.*

⁷ Also drawn from the Value of Informal Care in 2020.

week.⁸ Unpaid carers are said to have provided 2.2 billion hours of care nationally in 2020, saving the Australian Government \$77.9 billion annually.⁹

Carers SA notes the following:

People become Carers in different ways. Sometimes they start helping someone out bit by bit. Sometimes it happens suddenly, because of an accident or illness. Carers can be any age. Parents, grandparents, partners, siblings, children, friends and neighbours may all take on a caring role at some point in their life.¹⁰

Furthermore, many carers have reported that they live with disability (and presumably other challenges) themselves. In general, carers may also experience significantly poorer health, higher levels of financial stress, significantly lower wellbeing, and higher levels of psychological distress.¹¹ The situation of carers is also a gender issue given the increased impact on women when compared to men. Particular challenges are faced by young carers.

1.3.2 Government support

While the scope of the review does not relate to the provision of services or funding, it is important to recognise the broader context that applies to carers.

For example, the Commonwealth Government provides the majority of support for carers in their role, including by providing funding for the following:

- The *Carer Gateway* which provides in-person and online supports and services for carers.
- The Young Carer Bursary Program which provides bursary packages for eligible young carers aged 25 years and under.
- MyTime Peer Support Groups for Parents of Young Children with Disability which is an Australia-wide network of peer support groups of parents and carers of young children with disability or a chronic medical condition.
- A range of other payments to assist carers in their roles.

The State Government provides funding which complements Commonwealth funding.

In addition, the Department of Human Services (**DHS**) funds a range of carer-related roles and functions, including in connection with the administration of the *Carers Recognition Act 2005*, and by providing funding support within budget allocations for carers in South Australia. For example, carer support services have been funded under the *Community Connections Program*

⁸ See https://www.carersaustralia.com.au/about-carers/who-is-a-carer/

⁹ See https://www,carerssa.com.au.

¹⁰ See https://www.healthdirect.gov.au/partners/carers-sa

¹¹ See the 2022 National Carer Survey and the 2022 Carer Wellbeing Survey.

since 1 July 2021 to 30 June 2023, and from 1 July 2023 there has been a shift of focus in DHS's investment in carer support services, with the establishment of a specific Young Carer Support Service model (*YCSS*) provided by four State-funded carer support services. The service has been deliberately designed to complement (but not duplicate) "Carer Gateway" services by focusing on dedicated support for young carers¹², and breaks for carers¹³. Adult carers will continue to be supported to access the Carer Gateway and can still access short-term support as a priority cohort in the Community Connections Program.

The four organisations that are funded to deliver various programs, and comprise the South Australian Carer Support Network, are:

- Carers SA
- Carer and Community Support (CCS)
- Carers and Disability Link (CADL)
- Centacare Catholic Family Services (Northern Carers Network)

Carers SA is also the Carer Gateway lead in South Australia and the State's peak body for carers. DHS provides funding to Carers SA to assist in its support and advocacy for South Australian carers.

DHS also provides grant funding to support Grandcarers SA's "Our Village Program", which facilitates service delivery across all regions of South Australia.¹⁴

An important aspect of carer recognition and support is training and capacity building for service providers to improve support to carers, and training and assistance to carers, especially carers who may lack confidence in their role. The provision of helpful information in a way or form that carers can easily understand is also very important. DHS has a variety of programs that recognise these needs.

1.4 Overview of Act

The Act is a relatively simple piece of legislation. It has two stated objects as follows:

(a) to recognise and support carers in their role in the community;

¹² This program is intended to provide intensive support for young carers to improve their wellbeing, educational and employment outcomes, and to better prepare them to receive appropriate support under the "Carer Gateway".

¹³ Carers SA is being funded to provide carer breaks for carers of all ages to support social connection and to provide a complete break from caring duties to support a carer's wellbeing.

¹⁴ Grandcarers SA was formerly known as Grandparents for Grandchildren SA. The Villages are based on a mixture of metropolitan and regional areas, and are intended to provide support for grandparents and kinship carers in their caring roles.

(b) to provide for the reporting by organisations of the action taken to reflect the principles of the Carers Charter in the provision of services relevant to carers and the persons they care for.¹⁵

The Act seeks to recognise the role of carers in the community by requiring:

- (a) an applicable organisation to take all practicable measures to ensure that the organisation and its officers, employees or agents have an awareness and understanding of the Carers Charter, and to take action to reflect the principles of the Charter in the provision of relevant services;¹⁶ and
- (b) an applicable organisation that is a public sector agency to consult with carers, or their representative bodies, in policy or program development, or in strategic or operational planning, relevant to carers and the persons they care for;¹⁷ and
- (c) a reporting organisation to prepare a report on the organisation's compliance with its obligations under the Act, with the report to include any information prescribed by the regulations.¹⁸

The term *applicable organisation* is defined as being a *reporting organisation*, a person or body providing relevant services under a contract with a reporting organisation, or a person or body prescribed by the regulations.

The term *relevant services* relates to services that are relevant to carers and the persons they provide care for.

A *reporting organisation* is an administrative unit (or department) of the Public Service that provides relevant services (or any other person or body prescribed by the regulations but no regulations have been made under the Act).

Under current arrangements, the following departments of the State Public Service are considered to be *applicable organisations* and *reporting organisations*:

Department of Human Services Department for Health and Wellbeing Department for Education Department for Industry, Innovation and Science Department for Infrastructure and Transport

¹⁵ See section 3 of the Act.

¹⁶ See section 6(1) of the Act.

¹⁷ See section 6(2) of the Act.

¹⁸ See section 7 of the Act.

South Australian Police Department

TAFE SA

The concept of who is a *carer* is fundamental to the Act. Section 5(1) of the Act currently provides as follows:

A person is a *carer* if they are a natural person who provides ongoing care or assistance to –

- (a) a person who has a disability within the meaning of the *Disability Inclusion Act 2018*; or
- (b) a person who has a chronic illness, including a mental health illness within the meaning of the *Mental Health Act 1993*; or
- (c) a person who, because of frailty, requires assistance with the carrying out of everyday tasks; or
- (d) a person of a class prescribed by regulation.¹⁹

However, a person is not a carer if they provide care or assistance under a contract for services or a contract of service, or in the course of doing community work by a community organisation within the meaning of the *Volunteers Protection Act 2001*.²⁰ Also, a person is not a carer for the purposes of the Act only because the person is a spouse, domestic partner, parent or guardian of the person to whom the care or assistance is being provided, or provides care to a child who has been placed in a formal care arrangement under legislation.²¹

As mentioned in the *Issues Paper*, the South Australian Carers Charter provides a set of principles that must be applied under section 6 of the Act and provides legislative recognition to the status and role of carers in their interaction with organisations that are subject to the operation of the Act. The principles currently set out in the Charter are grouped under the following headings:

- 1. Carers have choices within their caring role.
- 2. Carers health and well-being is critical to the community.
- 3. Carers play a critical role in maintaining the fabric of society.
- 4. Service providers work in partnership with carers.
- 5. Carers in Aboriginal and Torres Strait communities need specific consideration.
- 6. All children and young people have the right to enjoy life and reach their potential.

¹⁹ No regulations have been made under the Act.

²⁰ See section 5(2) of the Act.

²¹ See section 5(3) of the Act.

7. Resources are available to provide timely, appropriate and adequate assistance to carers.

The Act is essentially principles-based legislation. It does not give carers legal rights or entitlements. It does, however, impose obligations on public sector agencies to ensure that carers are recognised and supported.²²

All States and Territories, and the Commonwealth, now have their own recognition Acts.

1.5 First review of Act

As already mentioned, this is the second formal review of the Act.

First review – November 2012

The first review was initiated 5 years after the commencement of the Act and primarily related to the operation and effectiveness of the Act.^{23.} The report of the review was tabled in the South Australian Parliament in November 2012 (the *First Review Report*).²⁴

A key focus of the first review related to the obligations of relevant organisations to promote an awareness and understanding of the Carers Charter under the Act and to take action to reflect the principles of this charter in the provision of services, and reporting obligations under the Act. The review considered whether these obligations were being met, whether there were impediments to the meeting of these obligations, whether carers were being recognised and supported, and whether amendments to the Act would further support carers and their role in the community.²⁵

While the first review found that there was a "level of compliance with the Act, and that carers are reporting better recognition and support than prior to the enactment of the legislation", it went on to say that "the extent to which obligations are being met is inconsistent". It found that there were "a number of issues that are impeding the meeting of obligations by service providers and there are other issues preventing carers fully benefitting from the legislation".²⁶

It summarised its findings as follows:

Impediments to the meeting of legislative obligations by service providers

²² The same point was made by the *Report of the statutory review of the Carers (Recognition) Act 2010* Department of Family and Community Services (NSW) November 2016.

 $^{^{23}}$ See section 9 of the Act. The review was carried out in 2010 – 2011.

²⁴ Review of the Operation and Effectiveness of the *South Australian Carers Recognition Act 2005 – November 2011* Prepared by the Office for Carers, Department for Communities and Social Inclusion and laid on the Table of the House of Assembly (South Australian Parliament) 28 November 2012.

²⁵ See page 4 of the First Review Report.

²⁶ See page 4 of the First Review Report.

- Lack of awareness and understanding by some service providers of their obligations under the Act
- Lack of identification of carers by some service providers
- Lack of sensitivity and adequacy of response of some employees of service providers
- Difficulty in identifying carers able and willing to be engaged in policy or program development
- Insufficient respect for the knowledge carers can bring to policy and program development

Other issues preventing carers fully benefiting from the legislation

- Lack of awareness and understanding of the Act by carers
- Confusion with respect to the term "carer" and lack of identification with the term by carers

Matters for legislative amendment to further recognise and support carers

- Inclusion of former carers
- Inclusion of employees who are carers
- Strengthening of Carers Charter
- Determination of appropriate complaint mechanism with legislative change as required
- Strengthening of reporting requirements²⁷

A series of recommendations were made (23 in total), and these may be summarised as follows.

- (1) Recommendations about the adoption and application of the Carers Charter, and improving an understanding of the principles of the charter.
- (2) Recommendations to improve the involvement of carers in policy and program development.
- (3) Recommendations to improve reporting requirements.
- (4) A recommendation to maintain and increase strategies to increase carers' awareness and understanding of the Act.
- (5) A recommendation that the Act be reviewed on a regular basis.

²⁷ See page 4 of the First Review Report.

- (6) A recommendation about continuing to inform the community of the definition of "carer" under the Act.
- (7) Recommendations about recognising foster carers, former carers, and carers even if care recipients move to a residential facility.
- (8) Recommendations about improvements to human resource policies to assist carers.
- (9) Recommendations relating to changes to the Carers Charter.
- (10)Recommendations relating to the *Health and Community Services Complaints Act* 2004 to include carers as complainants, and proposing an amendment to that Act, and regulations under that Act, relating to complaints about applicable organisations failing to reflect the principles of the Carers Charter.

Response to first review

The Department (then the Department for Communities and Social Inclusion) then prepared a response to the review, called *We Care – Our Plan for South Australian Carers – Implementing the South Australian Carers Recognition Act 2005 and recommendations from its review* (the **We Care plan**).

The plan focused on the needs of "carers in their own right". Consistent with the approach of the Act, the plan's focus was on the public sector and the perceived need to ensure that the public sector is informed and responsive to issues and needs of carers in the State, including carers who interact with government services and carers who are government employees. Aspects of this plan will be discussed at a later point in this paper, but the following are noted as priorities for action under the plan:

- **Priority 1:** Government is an employer of choice for carers.
- **Priority 2:** Government and Government-funded services are addressing the social, emotional and physical needs of carers.
- **Priority 3:** Carers feel empowered to make choices within their caring role, and their choices are respected.
- **Priority 4:** Strategies are in place to address the specific needs of Aboriginal carers.
- **Priority 5:** Strategies are in place to address the specific needs of young carers.
- **Priority 6:** Strategies are in place to address the specific needs of carers from culturally and linguistically diverse (CALD) backgrounds.
- **Priority 7:** Strategies are in place to support former carers during and after their transition from the caring role.

1.6 Key matters

As stated by Carers Australia in one of its documents prepared for the *House of Representative Standing Committee on Social Policy and Legal Affairs: Inquiry into the recognition of unpaid carers*, it is "essential to appreciate the diversity of caring, as caring sits with a broader social, economic and cultural context and involves dynamic interconnections and ongoing shifts in relationships across the life course".²⁸ Carers Australia also makes the point that this involves diversity within and between carers as individuals, care relationships, and the people being cared for.²⁹

The reviewer has been impressed by the dedication of carers and immediately noted the varied and demanding circumstances that they face. Despite the fact that carers comprise such a significant part of our community and make such a significant contribution to our community, it appears that carers are still not recognised to the extent that they should be. This is also despite the work being undertaken by key State government departments, including by the provision of funding, and despite the work and activities of many non-government organisations, and the reviewer has been impressed by the efforts and commitment of the public servants and private sector personnel encountered during the course of the review to improve carer recognition.

The reviewer considers that more needs to be done to acknowledge the value of carers, both in relation to service delivery and in taking their views into account in connection with service design. It is also necessary for greater recognition to be given to the fact that often services provided to people require some involvement with carers. Carers have a lot to offer. They have lived experience and want to make a difference.

It is also important to recognise that carers need support themselves, and by supporting carers better outcomes can be expected for the people who are actually receiving the services.

The result is that Government departments and service providers should: (1) actively seek to identify carers; and (2) work with a carer to achieve the best outcome for the person for whom the carer is working to support; (3) provide as much support to a carer as is reasonable in the circumstances; and (4) recognise that carers have their own needs within and beyond their role as carers. The result can be much more effective and sustainable outcomes for the persons for whom carers are seeking to support and for the community more generally.

A number of themes started to emerge the course of the review, including that carers are essentially wanting:

- (1) recognition and identification;
- (2) an unimpeded ability to be able to provide the relevant care, including the ability to access services smoothly on behalf of the person whom they are caring for;

²⁸ See Submission 111 by Carers Australian to the *House of Representative Standing Committee on Social Policy and Legal Affairs: Inquiry into the recognition of unpaid carers* at page 5.

²⁹ This is also from Submission 111 by Carers Australian to the *House of Representative Standing Committee on Social Policy and Legal Affairs: Inquiry into the recognition of unpaid carers* at page 5.

- (3) flexible working arrangements and support from their employers (if a carer has a job);
- (4) the ability to be able to be involved in relevant policy or program development, and the ability to advocate for change;
- (5) the provision of good information to support carers in what they do;
- (6) more support and respite; and
- (7) the ability to complain if they feel that they are being unreasonably prevented from providing necessary care.

It is also important to stress that recognition is not just about providing a form of thanks or appreciation to carers. While this is important, many carers hope that the legislation assists in reducing or removing barriers to carers carrying out their caring roles. This is also important to government departments and agencies as, without carers, many systems and services would not work as well or could not be delivered effectively.

It also became apparent during the course of the review that there is support for greater alignment between the South Australian and the Commonwealth *Carer Recognition Act 2010*, especially in relation to key concepts, objectives and definitions. As noted in one submission, this will "assist State authorities to consolidate strategic approaches and policy directions to encompass both national and State aims".

In summary, and as stated in Carers SA submission for the purposes of the Review:

Further scope for improvement to the Act includes provisions for active Carer involvement in the development of legislation, policy, and service decision-making processes that impact Carers' wellbeing, their caring role, or impact on financial security, work-life, social connections, and life aspirations.³⁰

1.7 List of recommendations relating to legislation

The following is a list of the recommendations that are being made as a result of the review that relate to the amendment of the Act or related legislation. The recommendations are set out in the order in which they appear in this report.

- 1. Section 3 of the Act should be amended so that the objects of the Act are:
 - (a) to increase recognition and awareness of carers and to acknowledge the vital contribution that carers make to the community; and
 - (b) to support carers in their role in the community; and

³⁰ See Carers SA Submission to the Review the South Australian Carers Recognition Act 2005 assessing the *effectiveness of the Act and its principles in practice* 15 December 2023.

- (c) to provide for the reporting by public sector agencies of the action taken to reflect the principles of the Carers Charter in the provision of services relevant to carers and the persons they care for.
- 2. The following amendments should be made to the Act in relation to the meaning of "carer":
 - (1) The reference in section 5(1) to a person who provides "ongoing care and assistance" should be replaced with "personal care, support or assistance". This would provide greater consistency with the Commonwealth Act, section 5(1).
 - (2) Section 5(1)(b) should refer to a person who has a medical condition (including a terminal or chronic illness or dementia), or a mental illness. This would provide greater consistency with the Commonwealth Act, section 5(1)(b) and (c), and there was significant support for making express reference to dementia.
 - (3) Section 5(1)(c) should refer to a person who, because of frailty or some other condition or circumstance, requires assistance with the carrying out of everyday tasks.
 - (4) Section 5(1) should be amended to include the following additional categories of persons who provide personal care, support or assistance to:
 - (a) a child or young person, if the person providing the care, support or assistance is the primary informal kinship carer of the child or young person;
 - (b) a person who has alcohol or other drug dependence.
 - (5) The Act should be amended to allow the carer of a person who has moved into a residential facility to continue to be recognised as a carer to the extent that they continue to assume an advocacy role relating to the welfare or wellbeing of the care recipient.
- 3. A definition of "personal care" should be considered if the term is used in amendments to the Act.
- 4. Options for a revised definition of "carer" should be the subject of further consultation with carers, stakeholders and representative groups, and take into account any reforms proposed by the Commonwealth.
- 5. Section 5(2) and (3) should be consequentially amended as required on account of amendments made to section 5(1).
- 6. Section 5(2) should be amended to include a new paragraph that refers to a person who provides care, support or assistance as part of the requirements of a course of education or training.
- 7. Section 5(3) should be amended so that a person is not a carer "merely because" they fall within a specified category of persons (rather than using the work "only").

- 8. The definition of "relevant services" in the Act should be amended so that it is consistent with the definition of "care supports" in the *Carer Recognition Act 2010* (Commonwealth).
- 9. The definition of an "applicable organisation" should be amended so that all public sector agencies (government departments and statutory authorities) are subject to the requirements in section 6 of the Act.
- 10. Section 6 should be replaced with the following provisions, together with further provisions referred to in the following recommendation, that provide as follows (consistent with the Commonwealth Act):
 - (a) each public sector agency is to take all practicable measures to ensure that its employees and agents have an awareness and understanding of the Carers Charter; and
 - (b) each public sector agency's internal human resource policies, so far as they may significantly affect an employee's caring role, are to be developed having due regard to the Carers Charter.
- 11. In replacing section 6, the following provisions should also be included (consistent with the Commonwealth Act):
 - (a) each public sector agency is to take all practicable measures to ensure that it, and its employees and agents, take action to reflect the principles of the Carers Charter in the provision of relevant services;
 - (b) each public sector agency is to consult carers, or bodies that represent carers, when developing or evaluating relevant services.
- **12.** Section 7(1) of the Act should be replaced with a provision that requires that each public sector agency to prepare a report on:
 - (a) compliance with the requirements set out in section 6 (as provided by the preceding recommendations); and
 - (b) actions which support the wellbeing of its employees who are carers; and
 - (c) how the agency's employees are being trained and educated to recognise and support carers, including Aboriginal or Torres Strait Islander carers and carers from cultural or linguistically diverse backgrounds.
- 13. The Carers Charter, clause 2 should be amended to include the following as a new subclause:

Support for carers should be timely, responsive, appropriate and accessible.

14. The Carers Charter, clause 5(3) should be amended so that it refers to the provision of culturally appropriate support services being provided in a *timely manner*.

- 15. The Carers Charter, clause 6(2) should be amended so that greater emphasis is given to the special needs of children and young people who are carers, including in relation to additional support, time out and guidance.
- 16. The Carers Charter, clause 6 should be amended to include the following as a new subclause:

Children and young people who are carers are entitled to participate fully in education and training and supported to do this.

- 17. A separate principle should be included to recognise carers from culturally and linguistically diverse backgrounds.
- 18. The Carers Charter should also recognise that cultural well-being is important for carers.
- 19. The specific needs of ageing and carers with disability should be recognised in the Carers Charter.
- 20. The Carers Charter should be amended to include a further principle relating to the advocacy and support role that a carer may need to perform if the person they have been caring for moves into a residential care facility.
- 21. The *Health and Community Services Complaints Act 2004* should be amended to give a carer a direct right to lodge a complaint under that Act on behalf of a care recipient in relation to the provision of a health or community service to the care recipient.
- 22. The Act should be published in an Easy Read format on the department's website after any amendments flowing from this report have been made and brought into operation.
- 23. A copy of this report should be published in an Easy Read format on the department's website, and made available by the department, after the report has been released to the public.
- 24. The Act should be amended so that another review is conducted at an appropriate time, which is recommended to be 5 years after any amendments to the Act as a result of this review have been submitted and passed by the Parliament.

1.8 Key terms and acronyms used in this report

The following are key terms and acronyms used in this report:

Act is the Carers Recognition Act 2005, which is the legislation that is the subject of this report.

Carers Charter is the South Australian Carers Charter that is set out in Schedule 1 of the Act.

Commonwealth Act is the *Carer Recognition Act 2010* Commonwealth.

the department or DHS is the Department of Human Services.

First review is the first review of the Act. ^{31.}

First Review Report is the report for the First review, tabled in the South Australian Parliament in November 2012.

Issues Paper is the paper that was prepared and released for the purposes of this review to facilitate discussion and to assist with the preparation of submissions.

public forum is the public forum that was held as part of the review on 27 November 2023.

stakeholder workshop is the workshop for interested parties, stakeholder and representative organisations, and several government agencies and entities, that was held as part on the review on 7 December 2023.

We Care plan is the Department for Communities and Social Inclusion's response to the First review, called *We Care – Our Plan for South Australian Carers – Implementing the South Australian Carers Recognition Act 2005 and recommendations from its review.*

 $^{^{\}rm 31}$ See section 9 of the Act. The review was carried out in 2010 – 2011.

2 Objects and definitions

2.1 Objects

As stated in the *Issues Paper*, the objects of an Act set the scene for describing its purpose. As already mentioned, the current objects of the Act as follows:

- (a) to recognise and support carers in their role in the community;
- (b) to provide for the reporting by organisations of the action taken to reflect the principles of the Carers Charter in the provision of services relevant to carers and the persons they care for.³²

The reviewer was keen to see whether it was thought that these objects are clear and adequate.

The objects were discussed both at the public forum and the stakeholder workshop, and at a variety of meetings conducted for the purposes of the review. A common theme, and as expressly picked-up on in at least one submission received by the reviewer, is that greater emphasis should be placed on the vital role and contribution of carers in the community. Taking this into account, the reviewer believes that section 3(a) of the Act should be replaced with the following:

- (a) to increase recognition and awareness of carers and to acknowledge the vital contribution that carers make to the community; and
- (ab) to support carers in their role in the community.

A consequential amendment will also need to be made to the object set out in section 3(b) of the Act to take into account a later recommendation in this paper.

Recommendation:

Section 3 of the Act should be amended so that the objects of the Act are:

- (a) to increase recognition and awareness of carers and to acknowledge the vital contribution that carers make to the community; and
- (b) to support carers in their role in the community; and
- (c) to provide for the reporting by public sector agencies of the action taken to reflect the principles of the Carers Charter in the provision of services relevant to carers and the persons they care for.

³² See section 3 of the Act.

2.2 Defined terms

2.2.1 Meaning of carer

Preliminary

As would be expected, an important aspect of the review has been to consider whether changes should be made to the meaning of "carer" under the Act.

The current definition essentially has two aspects, being:

- (1) that care and assistance must be *on-going* care and assistance; and
- (2) that the person who receives the assistance must be:
 - (a) a person with a disability; or
 - (b) a person with a chronic illness, including a mental health illness; or
 - (c) a person who requires assistance with carrying out everyday tasks because of frailty.³³

First review

As mentioned in the *Issues Paper*, the First Review of the Act discussed this definition and made several recommendations.³⁴ These recommendations were:

- (1) That the (former) Office for Carers and carer support organisations continue to inform the community of the definition of *carer* in the Act in order to counter the confusion that arises with respect to the term.
- (2) That a determination be made as to whether foster carers providing ongoing care or assistance to a child with a disability or chronic illness should fall within the definition of carer for the purposes of the Act and ensure the Act reflects that determination.
- (3) That the Act be amended to
 - include former carers in the Act and the Carers Charter;
 - make it clear that if a care recipient moves to a residential facility that person's carer is still a carer unless he or she has ceased to provide ongoing care or assistance.

³³ See section 5(1) of the Act. It is noted that other classes of persons may be prescribed by regulation, but this has not been done to date.

³⁴ See especially pages 33 – 35 of the First Review Report.

Some additional categories

As would be expected, the meaning of "carer" was the subject of various discussions and submissions during the course of the review. For example, it has been suggested that:

- (a) caring for a person who has an alcohol or other drug dependency should be included to improve clarity; and
- (b) formal foster carers and kinship carers should be included in the definition; and
- (c) grandparents who are caring for grandchildren should be included in the definition.

As to formal foster carers, one submission said foster carers are recognised as being "a backbone to our caring system", and it was submitted that it is importance to highlight their importance in the community and that recognition may encourage others to take on this role. However, this is not really an object of the Act and responsibility for promoting foster care is better placed with the Department of Child Protection. It is also considered that these people are more in the nature of parents and, as was the case with the First Review, it has been concluded that foster parents should not be specifically referred to in the legislation.

As to kinship carers, a starting point is to consider the role of grandparents who must look after their grandchildren and possibly their great grandchildren. It has always been the case that many grandparents look after their grandchildren but there is no doubt that greater reliance is being placed on grandparents, who may experience significant demands and disadvantages in undertaking this caring role. This role may be assumed in a variety of circumstances, including where a grandchild is placed with a grandparent by a government department. In such a case, this may be a significant caring role but it is not recognised under section 5(1) of the Act. A similar role may be assumed by aunts or uncles, siblings or other relatives or even family friends.

Grandparents and other relatives who are carers are often referred to as "informal kinship carers", and the recognition of such carers was recommended in a number of submissions and discussions, including the submission that was made by *Grandcarers SA*. This term and concept may also work well for some situations with Aboriginal and Torres Strait Islander children and young persons where kinship caring occurs.³⁵

It is also worth noting that some of the corresponding Acts in other jurisdictions include carers who are "kinship carers" for children or young persons.³⁶

³⁵ As mentioned in one submission, kinship carers, informal part-time carers, family carers, and carers across community groups, all provide part of a safety net associated with the care of people and especially children. The concept of a kinship carer who is an Aboriginal or Torres Strait Islander person is also recognised under the *Equal Opportunity Act 1984* – see section 5(3)(b).

³⁶ See, for example, the *Carers Recognition Act 2021* (ACT).

Short term illnesses or provision of temporary care

Another suggestion was that the definition should include carers of people who may not have a diagnosis of a chronic illness, and carers of people with transient or short-term illnesses or where the giving of care is temporary.³⁷ In this regard, the reviewer considers that it may well be unduly limiting to require that a person must provide "ongoing care or assistance" in order to be recognised as a carer as, for example, a person with a short-term illness may need the same assistance as a person who needs on-going care or assistance. The question should be whether a person needs the support of a carer, not how long the support may be needed.

Public and stakeholder discussion

The concept of a carer was extensively discussed at both the public form and the stakeholder workshop conducted for the purposes of the review.

Participants at the public forum included people who are caring for Vietnam war veterans, for people living with disability, for people with poor mental health, and for older people. They noted that a lot of people do not recognise or appreciate the role of carer and that a lot of carers, especially young people, do not think of themselves as carers. It is the reviewer's assessment that many members of the public who are undertaking a role that involves the care or support of another person would support a "wide" definition of "carer".

In the case of the stakeholder workshop, a number of participants supported the idea that the meaning of carer should be "expanded". For example, it was suggested that the requirement that a person must provide "on-going care" should be removed, and that short-term illnesses should be included, as also discussed above, and that the reference to frailty should be removed. It was also suggested at the stakeholder workshop that informal kinship carers, also discussed above, should be included. In summary, there also appeared to be support for a "wide" definition at the workshop.

General support - submissions

The proposal that a wider definition of carer be adopted was also supported in a number of submissions. For example, it was said in one submission that anyone providing significant care and support to another individual who needs assistance due to illness, disability, old age, or other challenges should be considered to be a carer. This should include both formal and informal carers, irrespective of age, relationship or specific circumstances. It was also said in a submission that the Act should recognise carers regardless of whether the care recipient has transitioned to residential care, and that the Act should recognise former carers. As noted in one submission, the carer of a person who moves into a residential facility should be recognised because carers have an advocacy role relating to the welfare or wellbeing of care recipients. This would often also be the case for a person who has ceased to be an actual "carer" for some reason; the person may still be interested in the welfare or wellbeing of the former care recipient.

³⁷ This suggestion was made by *Carers and Disability Link* in their submission for the review.

There was also support for making express reference to the carers of people with dementia, which may not be seen as a chronic condition in some cases and is certainly a very common condition in the community.

The reviewer understands that the scope of the Act is a matter of judgment and balance. In undertaking the review, it is clear that people are seeking greater recognition and support in their role as carers. They may not be interested in whether or not they technically fall within the scope of a particular definition, but rather that barriers are removed and services provided, and that they can gain such things as recognition, support and respite. So, for example, a person who takes on a caring role on a short-term basis may well have the same experiences and challenges as someone who has been undertaking that role on a long-term basis. A person who has been caring for another person may well not lose their connection and concern for the other person just because they move into a residential facility. This type of law should reflect the needs and interests of persons who are fulfilling this important role in our community.

Recommendation

As a result of the discussions during the course of the review and submissions, the reviewer believes that a number of changes should be made to the meaning of "carer" under the Act.

Recommendation:

The following amendments should be made to the Act in relation to the meaning of "carer":

- (1) The reference in section 5(1) to a person who provides "ongoing care and assistance" should be replaced with "personal care, support or assistance". This would provide greater consistency with the Commonwealth Act, section 5(1).
- (2) Section 5(1)(b) should refer to a person who has a medical condition (including a terminal or chronic illness or dementia), or a mental illness. This would provide greater consistency with the Commonwealth Act, section 5(1)(b) and (c), and there was significant support for making express reference to dementia.
- (3) Section 5(1)(c) should refer to a person who, because of frailty or some other condition or circumstance, requires assistance with the carrying out of everyday tasks.
- (4) Section 5(1) should be amended to include the following additional categories of persons who provide personal care, support or assistance to:
 - (a) a child or young person, if the person providing the care, support or assistance is the primary informal kinship carer of the child or young person;
 - (b) a person who has alcohol or other drug dependence.
- (5) The Act should be amended to allow the carer of a person who has moved into a residential facility to continue to be recognised as a carer to the extent that they

continue to assume an advocacy role relating to the welfare or wellbeing of the care recipient.

Concept of personal care

In making these recommendations, consideration should also be given to whether a definition of "personal care" should be included. In relation to this issue, it is noted that the *Carer Recognition Act 2021* (ACT) provides that "personal care" means assistance with: (i) bathing, showering or personal hygiene; (ii) toileting; (iii) dressing or undressing; (iv) eating meals; (v) communicating; (vi) for a person with mobility problems – physical assistance; (vii) some other form of supervision or assistance; (viii) assistance or supervision in administering medicine; or (ix) the provision of substantial emotional support. The reviewer considers that it would be helpful to include a definition of "personal care" along these lines.

Recommendation:

A definition of "personal care" should be considered if the term is used in amendments to the Act.

Further consultation

How the Act identifies and defines who is a "carer" is a fundamental aspect of the Act. In view of the significance of this issue, it is further recommended that the various suggestions and options that have been considered, discussed and recommended by this report should be subject to further consultation and discussion with carers, stakeholders and representative groups before a final decision is made on the amendments that should be made in relation to this matter.

Furthermore, it was suggested in one submission that a completely different approach should be taken, which would define a carer as a person who provides ongoing personal care, support or assistance to a family member or friend that is above and beyond that expected in society in that relationship.³⁸ While this may not be the reviewer's preferred option, it is certainly worthy of consideration as part of a discussion about the best approach to defining a "carer" for the purposes of the Act.

Finally, it is noted that the report for the *Inquiry into the recognition of unpaid carers* was being undertaken by the House of Representatives Standing Committee on Social Policy and Legal Affairs includes a recommendation that the Australian Government works with the States and Territories to harmonise the definition of carer across all carer recognition legislation. A significant degree of national consistency is certainly worth considering, subject to ensuring that the "coverage" of the South Australian Act is not diminished (including after taking into the recommendations contained in this report).

Recommendation:

³⁸ This was suggested by Carers SA in their *Submission to the Review the South Australian Carers Recognition Act* 2005 assessing the effectiveness of the Act and its principles in practice 15 December 2023.

Options for a revised definition of "carer" should be the subject of further consultation with carers, stakeholders and representative groups, and take into account any reforms proposed by the Commonwealth.

2.2.2 Exclusions from the definition of "carer"

Any consideration of the meaning of "carer" has to be undertaken in conjunction with the "exclusions" that appear in section 5(2) and (3) of the Act.

Firstly, section 5(2) and (3) should be amended so that the passage "care or assistance" is consistent with the final approach taken in section 5(1) on account of the discussion in 2.2.1.

Secondly, the reviewer considers that the opportunity should be taken to amend section 5(2) to achieve greater alignment between the South Australian and the Commonwealth *Carer Recognition Act 2010* by adding an extra paragraph to refer to a person not being a carer if they provide care, support or assistance as part of the requirements of a course of education or training.³⁹

Thirdly, a submission suggested that section 5(3) could benefit from some clarification in relation to the use of the word "only".⁴⁰ Feedback has suggested that the use of "only" has the unintended consequence that carers who fall within a category of persons referred to in paragraph (a) or (b) of the subsection believe that they are excluded from the Act. In relation to this issue, it is useful to refer to the Commonwealth Act, and to the Carer Recognition Acts of other jurisdictions. So, for example, section 5(3) of the Commonwealth Act, which refers to a person not being a carer "merely because" the person falls into a specified category of persons. The reviewer considers that this approach should be adopted.

Recommendations:

- (1) Section 5(2) and (3) should be consequentially amended as required on account of amendments made to section 5(1).
- (2) Section 5(2) should be amended to include a new paragraph that refers to a person who provides care, support or assistance as part of the requirements of a course of education or training.
- (3) Section 5(3) should be amended so that a person is not a carer "merely because" they fall within a specified category of persons (rather than using the work "only").

³⁹ See section 5(2)(c) of the *Carer Recognition Act 2010* Commonwealth. This is also an exclusion in other jurisdictions – see, for example, section 4(4)(c) of the *Carers Recognition Act 2012* (Victoria) and section 6(4) of the *Carers Recognition Act 2021* (ACT).

⁴⁰ This was also suggested by Carers SA in their *Submission to the Review the South Australian Carers Recognition Act 2005 assessing the effectiveness of the Act and its principles in practice* **15** December 2023.

2.2.3 Definition of "relevant services"

Another key concept in the Act appears as the term "relevant services", which are currently defined as being "services relevant to carers and the persons they care for".

Unfortunately, this definition may be interpreted as referring to:

- (1) services that are "relevant" to both carers and the persons they care for, which would be unduly restrictive; *or*
- (2) almost all services provided by the State government in view of the involvement of carers in connection with so many services, which would be too wide.

In considering this question, it is again useful to turn to the Commonwealth Act. Under that Act, the term "care supports" is used, and this is defined as "policies, programs or services directed to carers or the persons they care for".⁴¹

In employing this definition, the Commonwealth has provided helpful advice about how this definition is interpreted and applied. This advice is found in guidelines prepared for the purposes of the Commonwealth Act.⁴² The guidelines provide that "care supports" refers to any "policy, program or service that targets carers as a priority group within Australia, or targets the people for whom they care". The guidelines go on to say that, for instance, care supports include policies, programs or services that are directly associated with carers, or with care recipients who have a high likelihood of requiring the support of a carer. It is also said that the term does not extend to "mainstream supports that are directed to society more broadly".⁴³

The reviewer considers that this is another place where the approach in the Commonwealth Act is preferable and should be adopted, but that it would be preferable to retain the more "neutral" term of "relevant services".

Recommendation:

The definition of "relevant services" in the Act should be amended so that it is consistent with the definition of "care supports" in the *Carer Recognition Act 2010* (Commonwealth).

⁴¹ See section 4(1) of the Commonwealth Act.

⁴² See Carer Recognition Act 2010 Guidelines – A guide for Australian Public Service Agencies for the implementation of the Carer Recognition Act 2010.

⁴³ See page 7 of the Commonwealth guidelines.

3 Relevant organisations and authorities

3.1 Organisations under Act

3.1.1 Preliminary

The Act imposes obligations on applicable organisations and reporting organisations.

As outlined in the *Issues Paper* and noted earlier in this paper, section 6 of the Act places certain obligations on *applicable organisations*, and section 7 places reporting requirements on *reporting organisations*.

3.1.2 Applicable organisations

As already mentioned, the term *applicable organisation* is defined as being a *reporting organisation*, a person or body providing relevant services under a contract with a reporting organisation, or a person or body prescribed by the regulations.

The term *relevant services* relates to services that are relevant to carers and the persons they provide care for.

A *reporting organisation* is an administrative unit (or department) of the Public Service that provides relevant services (or any other person or body prescribed by the regulations but no regulations have been made under the Act).

As stated in the *Issues Paper*, consideration could be given to providing that all State Government organisations, which includes departments and other public sector agencies, are "applicable organisations", and that "reporting agencies" are those departments and public sector agencies that have policies, programs or services that are specifically for carers.

The adoption of the position outlined in the *Issues Paper* in relation to "applicable organisations" would ensure that all such entities would be required to ensure that their employees and agents have an awareness and understanding of the Carers Charter.

Furthermore, the legislation could adopt a recommendation flowing from the First review so that all government departments and agencies include in their human resources policies a policy for carers employed in the department or agency that reflects the principles in the Carers Charter.⁴⁴

An "expanded" definition of "applicable organisation" and associated recommendations would also provide greater consistency with the Commonwealth Act, as section 7 of that Act provides as follows:

⁴⁴ The First review's recommendation on this point only referred to government departments, while the reviewer considers that any such initiative should extend to other public sector agencies as well.

- (1) Each public service agency is to take all practicable measures to ensure that its employees and agents have an awareness and understanding of the Statement for Australia's Carers.
- (2) Each public service agency's internal human resources policies, so far as they may significantly affect and employee's caring role, are to be developed having due regard to the Statement for Australia's Carers.

For the Commonwealth Act, a "public service agency" is an Agency within the meaning of the *Public Service Act 1999* (Commonwealth), and an Agency under that Act is a Department, Executive Agency and Statutory Authority. In turn, a Statutory Authority is a body or group of persons declared by a law of the Commonwealth to be a Statutory Agency for the purposes of that Act. Such entities would be statutory authorities in South Australia.⁴⁵

The Act should continue to extend to a person or body providing relevant services under a contract or a person or body declared by regulation to be an applicable organisation (as provided in the definition of "applicable organisation" in section 4.

Recommendation:

The definition of "applicable organisation" should be amended so that all public sector agencies (government departments and statutory authorities) are subject to the requirements in section 6 of the Act.

The recommendation that public sector agencies replace "applicable organisations" under the Act should then be considered in conjunction with the result that all such entities include in their human resources policies a policy for carers employed in the department or agency that reflects the principles in the Carers Charter, as indicated above. As said in one submission, this would promote carer support strategies, and it would also provide greater recognition to carers by the organisations and agencies that are tasked to implement and advance the objects of the Act. Indeed, it is recommended that section 6 of the Act should be replaced with a new set of provisions that provide, amongst other things, for these matters in a manner consistent with section 7 of the Commonwealth Act.

This would also be consistent with the department's response to the review entitled *We Care* – *Our Plan for South Australian Carers* – *Implementing the South Australian Carers Recognition Act* 2005 and recommendations from its review. In particular, Priority 1, entitled *Government is an employer of choice for carers*, presented the following outcomes:

Outcome 1: Employees with caring responsibilities are consulted in the development of human resource policy.

Outcome 2: Employees with caring responsibilities are recognised and supported through human resource policy

⁴⁵ Note: A local council is not considered to be a public sector agency or statutory authority in cases such as this.

Outcome 3: Flexible working arrangements and leave provisions are assisting employees with caring responsibilities to balance work and caring.

Outcome 4: Employees and managers are informed about carer-friendly policies and entitlements and about external assistance available to employees.

Recommendation:

Section 6 should be replaced with the following provisions, together with further provisions referred to in the following recommendation, that provide as follows (consistent with the Commonwealth Act):

- (a) each public sector agency is to take all practicable measures to ensure that its employees and agents have an awareness and understanding of the Carers Charter; and
- (b) each public sector agency's internal human resource policies, so far as they may significantly affect an employee's caring role, are to be developed having due regard to the Carers Charter.

3.1.3 Responsibilities towards carers

Provisions of the Act

Currently, section 6 of the Act also requires an applicable organisation that is a public sector agency to consult with carers, or persons or bodies that represent carers, in policy or program development, or strategic or operational planning, relevant to carers and the persons they care for. As already discussed in this report, it is considered that the term "relevant services" be amended so that it is consistent with "care supports" under the Commonwealth Act.

The consultation requirements of section 6 of the Act were discussed in the First Review Report. In particular, the report noted that consultation with carers and bodies that represent carers is occurring "in some instances".⁴⁶ However, the reasons for consultation not occurring as often as it could be were considered to include:

- the difficulties carers have in being involved due to lack of time and an inability to access respite to allow attendance
- the difficulties service providers have in finding carers able to be involved and in finding carers who feel they have something to contribute
- when carers are involved, they often feel their contributions are not valued and that service providers dominate and so do not feel it a worthwhile experience.

The First Review Report therefore recommended that those applicable organisations that are public sector agencies –

⁴⁶ See page 26 of the First Review Report.

- develop policies and guidelines to assist in the identification of carers willing to be involved in policy and program development;
- assist carers to be involved in policy and program development; and
- acknowledge and respect the knowledge and experience carers bring to this role.

Priority 2 of the We Care plan is relevant in this context. Priority 2 is: Government and Government-funded services are addressing the social, emotional and physical needs of carers, and this priority provides for the following outcomes:

Outcome 1: Carers have input into the development and review of programs and services that affect them

Outcome 2: Government agencies and their employees are aware of the specific needs of individual carers

Outcome 3: Services provided to the public accommodate the specific needs of individual carers

Outcome 4: Services provided to the public are accessible locally and able to adapt to the needs of local communities

As is to be expected, the extent to which carers and their representatives are consulted in relation to policy and program development, and strategic and operational planning, in relation to matters that are relevant to carers and the people they care for, was said to vary between government departments.

It is clear that some State government departments and agencies are doing an excellent job in consulting with carers and relevant organisations and in ensuring that carers are actively involved in policy, program and service development and implementation.

For example, the reviewer became aware of the *Partnering with Carers Policy Directive* in SA Health. This comprehensive policy directive builds on SA Health's commitment to improving the way in which it partners with carers and has as its stated purpose "to recognise and support carers and their roles" in their interactions with the South Australian public health system. It is particularly impressive in the way in which it views carers as being "partners in care", and is directly related to its *Consumer, Carer and Community Engagement Strategy Framework 2021 – 2025*, which sees consumer, carer and community engagement as being essential to health service culture, quality and safety and consumer-related care to better meet patient needs and preferences. Such outcomes are a direct result of engaging carers in program and service design and delivery.

However, it also clear that we need to emphasise and strengthen the need for a consultative approach with carers in connection with the development of relevant government programs, including by employing principles of co-design.⁴⁷

This is particularly important as in many cases services will be delivered to people who are being supported or assisted by carers.

The involvement of carers in this regard is also consistent with the requirements and principles of the Carers Charter – see, for example, Principles 3(2) and 4(4) and (5).

Recommendation:

In replacing section 6, the following provisions should also be included (consistent with the Commonwealth Act):

- (a) each public sector agency is to take all practicable measures to ensure that it, and its employees and agents, take action to reflect the principles of the Carers Charter in the provision of relevant services;
- (b) each public sector agency is to consult carers, or bodies that represent carers, when developing or evaluating relevant services.

Related issues

It was said during the review that the role of carers needs greater "validation" within our community. It was also said that many people consider that a "carer" is a paid care worker (which is inconsistent with the Act (and with corresponding legislation in other jurisdictions)).

It was also clear that there are many instances where carers are not identified, or a service provider has no visibility of, or fails to give any recognition to, a carer. It is important to encourage service providers to actively seek to identify if a carer is involved in supporting a particular service recipient, or potential service recipient.

The recommendation that the Act be amended so that each public sector agency is to take all practicable measures to ensure that its employees and agents have an awareness and understanding of the Carers Charter should assist in this regard.

3.2 Reporting

As mentioned in the *Issues Paper*, reporting is part of raising awareness of the need to take carers and the people they care for into account by State government organisations.

⁴⁷ In referring to co-design, it has been said that this is about people who use or are affected by a service or product being involved in the development or design of that service or product. As indicated by the NSW Council of Social Service, co-design is a process. It builds on engagement processes where critical stakeholders are encouraged to participate and are respected as equal partners, sharing expertise (and experience) in the design of services and products (and programs and policies could be added as well). The NSW Council of Social Service refers to the principles of co-design as being: (1) inclusive; (2) respectful; (3) participative; (4) iterative; and (5) outcomes focused.

Section 7 of the Act requires a reporting organisation to prepare a report on the organisation's compliance with the Act and, if a person or body provides relevant services under a contract with the organisation, that person's or body's compliance with the Act.

Recommendations made in the First Review Report in relation to this section were:

- (1) That reporting organisations require a report from each person or body that provides relevant services under a contract with the organisation as to the compliance of the person or body with the Act to enable the reporting organisation to fulfil the requirements of section 7(1)(b) of the Act.
- (2) That regulations be made prescribing matters to be included in a report of a reporting organisation, including requiring reports to specify each business unit within the organisation and the compliance of that unit with the Act. The focus of the regulations should be on attaining information in an efficient and consistent manner.
- (3) That reporting organisations be required to publish the organisation's report on compliance with the Act on the organisation's website and make the report available as a hard copy on request.

The earlier recommendation in this report that all public sector agencies replace "applicable organisations" under section 6 essentially means that there is no further need for the concept of a "reporting organisation". Rather, all public sector agencies should report on their responsibilities under the Act.

Furthermore, some of the submissions discussed how reporting could be improved, including by reporting on actions and outcomes associated with carer support and the extent to which consideration has been given to various groups within the community, such as carers from cultural or linguistically diverse backgrounds.

The reviewer considers that more should be included in the reporting requirements under the Act.

Recommendation:

Section 7(1) of the Act should be replaced with a provision that requires that each public sector agency to prepare a report on:

- (a) compliance with the requirements set out in section 6 (as provided by the preceding recommendations); and
- (b) actions which support the wellbeing of its employees who are carers; and
- (c) how the agency's employees are being trained and educated to recognise and support carers, including Aboriginal or Torres Strait Islander carers and carers from cultural or linguistically diverse backgrounds.

3.3 Related consideration – rights-based legislation

Some of the submissions proposed that the Act be amended so that it includes legally enforceable obligations, especially in relation to the recognition of carers "rights" set out in the Carers Charter.

No other jurisdiction in Australia has "rights-based" legislation. Rather, the focus in Australia is on legislation that: (1) recognises the importance of carers; and (2) provides for a statutory Carers Charter; and (3) requires public sector agencies to reflect the principles of the Charter in the development and provision of relevant services (however they are described).

It should also be noted that the entities to which the Act applies are public sector departments and agencies. The Act imposes obligations on these entities and government departments and agencies are expected to comply with all relevant legislation, including legislation that sets out various principles and other requirements that are not drafted as mandatory provisions. This may be viewed as an aspect of the rule of law – that the requirements of legislation should be adhered to and applied. The result is that legislation such as this is not usually drafted so as to create a set of "rights", but rather establishes principles and a framework which must be applied and adopted in accordance with, and to advance, the objects and purposes of the relevant Act.

The reviewer is aware that Carers SA has published its submission to the *Inquiry into the Potential for a Human Rights Act for South Australia,* in which Carers SA calls for the South Australian Government to set out succinctly, in one place, the rights necessary to ensure that all people – including carers – live with dignity and security.⁴⁸

The reviewer is particularly aware, as said by Carers SA in its submission, that carers "are often unheard, unseen, un-recognised and tend to put the needs of the person they support before their own wellbeing and health needs". Carers SA go on to say: "As a result of their caring role, a substantial number of Carers are not able to access social and economic benefits that are essential in living a fulfilling life.".

The reviewer does not seek to detract from Carers SA's view that the fundamental principles of dignity, equality and respect for carers, together with their wellbeing, are directly relevant to carers. The reviewer considers that any question of statutory rights should be considered as part of the development and implementation of a South Australian Human Rights Act rather than under the Act to which this review relates.

⁴⁸ See Carers SA submission to the *Inquiry into the Potential for a Human Rights Act for South Australia* at page 2: <u>https://www.carerssa.com.au/wp-content/uploads/2024/02/Carers-SA-submission-to-the-INQUIRY-INTO-THE-POTENTIAL-FOR-A-HUMAN-RIGHTS-ACT-FOR-SA-2024-Final.pdf</u>

4 South Australian Carers Charter

4.1 Proposals for change

As set out in the *Issues Paper*, the South Australian Carers Charter forms an important part of the Act. The Charter currently provides for principles grouped under the following headings.

- 1. Carers have choices within their caring role.
- 2. Carers health and well-being is critical to the community.
- 3. Carers play a critical role in maintaining the fabric of society.
- 4. Service providers work in partnership with carers.
- 5. Carers in Aboriginal and Torres Strait communities need specific consideration.
- 6. All children and young people have the right to enjoy life and reach their potential.
- 7. Resources are available to provide timely, appropriate and adequate assistance to carers.

As also discussed in the *Issues Paper*, the First Review Report made a series of recommendations in relation to the Charter.

As a result of this review, it is apparent that a series of recommendations from the First review should be adopted, and that some other changes could be made to fill some gaps. A series of recommendations relating to the content of the charter, which reflect many aspects of the discussion found in other parts of this report and submissions made for the purposes of the review, follow. In particular, it is considered that it would be helpful to place greater emphasis on certain matters through amendments to the Charter. This was seen as being particularly relevant to Aboriginal and Torres Strait carers, young carers, and carers in from culturally and linguistically diverse backgrounds.

In some cases, it was thought that additional subclauses should be added to the Charter, and in other places it was seen as a matter of adding to existing provisions.

Recommendations:

(1) The Carers Charter, clause 2 should be amended to include the following as a new subclause:

Support for carers should be timely, responsive, appropriate and accessible.

(2) The Carers Charter, clause 5(3) should be amended so that it refers to the provision of culturally appropriate support services being provided in a *timely manner*.

- (3) The Carers Charter, clause 6(2) should be amended so that greater emphasis is given to the special needs of children and young people who are carers, including in relation to additional support, time out and guidance.
- (4) The Carers Charter, clause 6 should be amended to include the following as a new subclause:

Children and young people who are carers are entitled to participate fully in education and training and supported to do this.

- (5) A separate principle should be included to recognise carers from culturally and linguistically diverse backgrounds.
- (6) The Carers Charter should also recognise that cultural well-being is important for carers.
- (7) The specific needs of ageing and carers with disability should be recognised in the Carers Charter.⁴⁹
- (8) The Carers Charter should be amended to include a further principle relating to the advocacy and support role that a carer may need to perform if the person they have been caring for moves into a residential care facility.

4.2 Related matter – the approach to drafting the charter

A number of submissions advocated for a change to the language of the Carers Charter so that it is expressed in stronger terms.

A scan of the legislation in other jurisdictions indicates that the South Australian Charter contains the most extensive and comprehensive set of principles (especially if the above recommendations for amendments to the charter are adopted). A number of corresponding Acts, including those that reflect the same approach as the South Australian Act in the drafting of their charters, also include provisions to the effect that the principles set out in the legislation do not create or confer any rights or entitlements enforceable at law.⁵⁰

One option would be to redraft the provisions of the Carers Charter so that it changes the emphasis of the language, but it would be necessary to also include a provision to the effect that the legislation does not create any right or entitlement, as provided in other jurisdictions. Consultation would be required if this proposal were to be considered. However, this approach is not recommended and the reviewer considers that the current approach is the preferable approach for such an instrument.

⁴⁹ See the discussion about the recognition of Older Carers in Carers SA's *Submission to the Review the South Australian Carers Recognition Act 2005 assessing the effectiveness of the Act and its principles in practice* 15 December 2023 at page 14. As Carers SA says: "Older carers are the only group in our community who cannot retire.".

⁵⁰ See, for example, section 10 of the *Carers Recognition Act 2012* (Victoria), section 9 of the *Carers (Recognition) Act 2010* (New South Wales) and section 12 of the *Carers Recognition Act 2021* (ACT).si

5 Recognition under other legislation

Carers are specifically recognised to some extent in other South Australian legislation.

For example, the *Equal Opportunity Act 1984* prohibits discrimination on the ground of caring responsibilities.⁵¹ The scheme under this Act was outlined in the *Issues Paper*. The *Issues Paper* also described how carers are recognised under the *Mental Health Act 2009*, the *Health Care Act 2008* and the *Fair Work Act 1994*.

As also mentioned in the *Issues Paper*, the First Review Report discussed whether a carer should be specifically included as a person who may make a complaint under the *Health and Community Services Complaints Act 2004* (as currently a carer may only lodge a complaint on behalf of another person if the Commissioner is satisfied that the carer should be able to make the complaint in the public interest). The result was a recommendation that the *Health and Community Services Complaints Act 2004* should be amended to give carers a "direct" right to lodge a complaint under that Act on behalf of a care recipient in relation to the provision of a health or community service to the care recipient. The reviewer considers that this recommendation is still valid and should be adopted.

Recommendation:

The *Health and Community Services Complaints Act 2004* should be amended to give a carer a direct right to lodge a complaint under that Act on behalf of a care recipient in relation to the provision of a health or community service to the care recipient.

⁵¹ See Part 5B of the *Equal Opportunity Act 1984*.

6 Additional strategies and initiatives

6.1 Preliminary

A number of other suggestions were made during the course of the review. This part of the report sets out the suggestions and recommendations that the reviewer considers should be adopted as they relate to the Act.

6.2 Additional strategies and recommendations

Easy Read documents

The Act is an important part of carer recognition in South Australia, but is not necessarily easily understood. It was suggested during the review that it would assist people who are not used to reading or understanding legislation if an Easy Read version of the Act could be prepared and made available on the department's website, especially after any amendments are made to the Act as a result of this report. It would also be helpful if an Easy Read copy of this report could be published on the department's website.

Recommendations:

- (1) The Act should be published in an Easy Read format on the department's website after any amendments flowing from this report have been made and brought into operation.
- (2) A copy of this report should be published in an Easy Read format on the department's website, and made available by the department, after the report has been released to the public.

Further review of Act

It is hoped that this review will lead to a more effective piece of legislation relating to carers recognition and support in South Australia. It is expected that this report will result in changes to the Act in due course.

It is not uncommon for modern Acts to require reviews to be conducted on an on-going basis to ensure that they continue to be relevant to circumstances to which they apply and continue to meet their objects and purposes.

This is the second formal review of the Act since it was enacted in 2005. It is thought that it would be useful to have another review in approximately 5 years time.

Recommendation:

The Act should be amended so that another review is conducted at an appropriate time, which is recommended to be 5 years after any amendments to the Act as a result of this review have been submitted and passed by the Parliament.