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Submission

*To the Review the South Australian Carers Recognition Act 2005
assessing the effectiveness of the Act and its principles in practice.*

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About Carers SA

Carers SA is a charitable for purpose organisation and is the recognised representative body for Carers in South Australia. Carers SA is also a service provider, offering a range of services to caring families in metropolitan, rural and remote locations across South Australia. Carers SA is the lead provider of federally funded Carer Gateway services in South Australia and state funded breaks for Carers across South Australia and supports for Young Carers in multiple locations across the state.

Carers SA is part of a National Network of Carer Associations and a member of Carers Australia – the recognised national peak body representing and advocating on behalf of family and friend Carers throughout Australia. We are a member of the Carer Support Network South Australia (CSNSA) and other human services-related networks. In addition, we work in partnerships and collaborations with others who support or conduct research with a focus on Carers, and with organisations that connect with Carer.

Carers SA collaborates with Carers via extensive Carer Advisory Groups, Carer forums and Round Table events across the state, as well as large qualitative and quantitative Carer surveys to inform our local, state, and federal advocacy work for Carers. We provide evidence-based advice to all levels of Government, business and service sectors to improve the Recognition of Carers and awareness of their service needs and preferences. Carers SA ensures that the voices of South Australian Carers are being heard by key decision-makers across the country and that these voices shape the way the organisation does business.

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. Caring however often comes at a cost to Carers with health and wellbeing consequences¹ and a degree of social isolation. A caring role is likely to impact an individual's work life and career as well as life aspirations which has a significant and lasting impact on Carers financial security². For example, Primary Carers will lose on average \$175,000 in superannuation and \$392,500 in lifetime earnings.

Although many (but not all) Carers report that they have taken on a caring role as part of their commitment to family, partners, or friends; Carers are very aware of the personal and financial sacrifices a caring role entails.

There are 2.7 million unpaid Carers in Australia. More than 856,000 Carers are primary Carers. South Australia's Carer numbers are estimated at 245,000 with nearly 30,000 Young Carers 24 years or younger.

*'Carers save the government thousands of dollars annually
Just imagine what would happen if we would stop doing what
we do. Recognition is often just tokenism.'*

Carer Comment

An evaluation of the "Value of informal care" undertaken by Deloitte Access Economics in 2020, estimated that the total cost to replace all family and friend care in that year would be \$77 billion³.

Carers are very aware of the contributions they make to the life of the people they care for and to Government budgets. Often this happens to the detriment of Carers' own financial security now and into the future. Therefore, many Carers have little or no capacity to future-proof themselves financially as they enter older age.

Availing Carers with formal and appropriate Recognition based on Carer rights, and a protected status demonstrates considered acknowledgement of the contributions Carers make to the community. We know that Recognition of Carers that is appropriately intentioned and translated effectively into practice has a positive impact on wellbeing and reduces stress for a Carer. It also strengthens health systems through the appropriate engagement of Carers as partners in care.

¹ See Report - 2022 Carer Wellbeing Survey, Available via: https://www.Carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf

² See Report Carers Australia – Caring Cost Us, available via <https://www.Carersaustralia.com.au/caring-costs-us>

³ Carers Australia – "The Value of Informal Care" Deloitte Access Economics available via: https://www.Carersaustralia.com.au/wp-content/uploads/2020/07/FINAL-Value-of-Informal-Care-22-May-2020_No-CIC.pdf

For over three decades, Carers SA has represented the Voice of South Australian Carers. This submission is based on the experiences and the input received from Carers across South Australia.

Recognition evidence underpinning this submission comes from the following data sources, the National Carer Survey SA content (2020 n:2255 & 2022 n:2248), the Carers SA – Carer Recognition Survey 2023 (n:689) and Round Table events held across South Australia between January and June 2023 (n:213).

Response Summary

- The Act served in the past to initiate aspirational Recognition of Carers in South Australia.
- Feedback received from Carers confirms that ‘the Act does not translate well or consistently into practice for Carers. Therefore, the purpose of the Act is not clearly demonstrated.
- There is no real discernible evidence (with the exception of SA Health’s Partnering with Carers Strategy and Department of Human Services funding for some Carer services) that the guidance provided by the Act to assure appropriate Recognition of Carers by Government departments and services (agencies under the Act) is as effective as it should be.
- Feedback from Carers received by Carers SA overwhelmingly demonstrates that the content of the current Act is making limited discernible positive differences in Carer lives.
- Community sentiment and expectations point clearly toward the need to allow the content of the Act to mature into a legal document that clarifies the rights and the status of South Australian Carers into the future.

Summary of Carers SA Recommendations

1. Strengthen the South Australian Carers Recognition Act and the wording of its South Australian Carers Charter to clearly state expectations and Carers’ Rights.
2. Inbuilt timeline for regular reviews of the Act itself.
3. Expand the reach of the Act to ensure Carer Recognition across all Government departments and agencies.
4. Formally investigate any required amendments or harmonisation across any other Act to ensure appropriate Recognition of Carers across sectors and jurisdictions.
5. Embed in the Act provisions for Ministerial Carer Advisory Committee structures across Government, to further the Recognition of Carers.
6. Embed expectations for an active approach to identifying Carers to ensure appropriate processes and actions are in line with the intentions of the Act’s core principles.
7. Redefine the definitions of a Carer and the subsequent exclusions under the Act.
8. Clarify the Rights of Young Carers and definitions in the Act related to Young Carers.
9. Set in place meaningful measures and public reporting on progress and outcomes for Carers. The Act should strengthen reporting requirements to be meaningful and represent a true measure of Carer Recognition practices.
10. The Act should include the requirement for a South Australian Carer Strategy with an embedded Carer Recognition Plan and regular consultative review processes, to support authorities under the Act with the implementation of the intentions of the Act.
11. Progress the establishment of a cross-departmental and stakeholder working group to allow for strategic collaboration and harmonising of supports for Young Carers across several Government departments’ portfolios, to ensure the achievement of education outcomes, career goals, life aspirations, and wellbeing.
12. Create a single central Carer feedback mechanism to support complaints and compliments to be lodged by Carers.

Suggested key purpose of the SA Carer Strategy and Carer Recognition Plan

- Clarify the roles of agencies under the Act.
- Clarify reporting content, outcome, and review timelines.
- Include policy, action, and outcome audits into a South Australian Carer Strategy.
- Set mechanisms in place to ensure that Government departments and their agencies consult with Carers and partner with Carers SA as the recognised representative body for South Australian Carers to collaborate on strategies that translate the Act into practice.
- Provide a mechanism that allows flexibility to respond to fluctuations in Carer demographics and need over time.

Response in Detail

Strengthening the Act – Rights and Expectations

While the South Australian Carers Recognition Act 2005 is an important guide toward recognising the contributions of unpaid Carers, it does not bind all public service agencies. The current Act ‘does not create legally enforceable obligation in judicial or other proceedings’, it should – and can be strengthened by stronger worded expectations around Recognition and Carer rights.

‘I think that all the SHOULDs should be removed and the PRINCIPLES be specific and measurable and all agencies be accountable for meeting them.’

Carer Comment

The following departments and agencies of the SA State Public Service are considered to be the authorities to which the current Act applies:

- Department for Education,
- Department for Health and Wellbeing,
- Department for Industry, Innovation and Science,
- Department for Infrastructure and Transport,
- South Australian Police Department,
- Department of Human Services,
- TAFE SA.

Since the Act’s inception in 2005 (and review in 2010) the level of practical commitment of government departments and agencies considered authorities under the Act has been vastly different. These range from a lack of identifiable formal Carer Recognition under the Act to sporadic activities on a localised level, to a systemic collaborative policy advisory and active partnership, as it exists between SA Health and Carers SA.

A key driver for Carer Recognition within the health care sector was the alignment of quality and safety programs to the National Safety and Quality Health Service Standards (NSQHS Standards second edition)⁴, after January 2019. These Service Standards were developed by the Commission in collaboration with the Australian Government, states and territories, private sector providers, clinical experts, patients, and Carers. The eight NSQHS Standards provide a nationally consistent statement about the level of care consumers can expect from health services. In particular, Standard 2 stipulates a Partnership with Consumers.

SA Health, after consultations with Consumers, Carers, and Carers SA expanded the focus of the NSQHS Standard 2 to formally recognise Carers with a focus on “*Partnering with Consumers*,

⁴ National Safety and Quality Health Services Standards – available online: [The NSQHS Standards | Australian Commission on Safety and Quality in Health Care](https://www.nsqhs.gov.au/)

Carers and the Community". SA Health's Governance Framework includes guides and toolkits to assist the health sector in partnering with consumers, Carers, and the community⁵.

SA Health's '*Partnering with Carers Strategy*⁶' developed in partnership with Carers SA laid out the formal Carer engagement and feedback processes and informed an official Partnering with Carer Policy. The [SA Health Partnering with Carers policy](#)⁷ was developed by SA Health in partnership with Carers SA and Carer representatives to reflect the priorities and needs of unpaid Carers and to establish principles and standards. The policy identifies what is important to Carers, based on feedback from Carers and includes clearly defined roles and responsibilities for SA Health staff.

The stated [key priorities](#)⁸ in the current policy include:

- **Early identification and Recognition.**
- Carers are engaged as partners in care.
- Carers provide comments and feedback.
- Carer friendly workplace
- Celebrate Carers during National Carers Week.
- Staff education and training.

In further detail, the Policy (Directive) states:

7.1 SA Health listens to Carers to understand what is important to them. This has led to the development of a set of principles. To support SA Health's implementation of the SA Carers Charter, SA Health commits to:

7.1.1 *Maintaining Carers as partners in care.*

7.1.2 *Recognising the different roles of Carers.*

7.1.3 *Treating Carers with respect, dignity and compassion.*

7.1.4 *Supporting Carers both in their caring role and in maintaining their own health and wellbeing.*

7.1.5 *Providing Carers with the right information about the care provided for the person they care for at the right time.*

7.1.6 *Providing guidance and direction to help Carers navigate the health system and transition of care decision making.*

7.1.7 *Ensuring services are flexible to the individual circumstances and needs of Carers and the people they care for.*

7.1.8 *Acknowledging Carers' unique long term perspectives.*

7.1.9 *Supporting Carers as informed advocates for a better health system.*

These good intentions set in policy in 2015 achieved some improvements in Carer Recognition, especially localised practice improvements, but these directives face quite significant practical implementation barriers without the backing of a rights-based SA Carers Recognition Act and appropriately detailed reporting requirements.

Note: The SA Health Partnering with Carer Policy is currently under review and includes consultation with Carers SA. The stated aim of the policy review is to further strengthen Carer Recognition within SA Health and Local Health Networks across South Australia.

⁵ SA Health: Partnering with Consumers, Carers and Community – available online: [Partnering with consumers, carers and the community | SA Health](#)

⁶ SA Health: Partnering with Carers: accessible online: <https://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Clinical+Resources/Safety+and+Quality/Partnering+with+Consumers%2C+Carers+and+the+Community/Carers+partnering+with+you>

⁷ Via SA Health Website: Partnering with Carers Policy – access: https://www.sahealth.sa.gov.au/wps/wcm/connect/064a90804a2136c38110e190d529bdaa/Directive_Partnering+with+Carers+Policy+Directive_110915.pdf

⁸ SA Health Partnering with Carers key priorities access via: https://www.sahealth.sa.gov.au/wps/wcm/connect/7ab8c073-ce0d-4580-b319-434507d8c18d/22086+Partnering+with+Carers_Factsheet_key+priorities.pdf

Recently, there were additional strategic collaborations between Carers SA and Local Health Networks (LHN) inputting into LHN strategic planning processes, community and Carer engagement strategies, general Carer Recognition across services and stronger early referral pathways for Carers to services.

Examples of the current projects under this partnership are available in the [Appendix](#).

Definition of Carer under the Act

We asked Carers whether the definition of Carers should be expanded. Carers suggested inclusions into the National Carers Recognition Act which would also apply as missing items in the current South Australian Carers Recognition Act:

Add 'has an alcohol and other drug dependency' to improve clarity	39.55%
- Support for this item is significantly higher for members of the LGBTIQA+ community	74.04%
- and from Carers with linguistically diverse family backgrounds	51%
Include formal Foster Carers and formal Kinship Carers into the definition of Carer under the Act	52.31%
Include Grandparents who are caring for grandchildren into the definition of Carers under the Act	70.65%
- Support for this item is significantly higher for member of Australia's First Nations Peoples	93%

Examples from the 117 Carer comments we received regarding the definition of Carer.

- *The person they care for has a trauma history of abuse and or neglect. This trauma is just as disabling or life-impacting and the person often exhibits the same behaviours has the same needs as someone with autism or ADHD for example but no recognised diagnosis.*
- *Anyone formal or informal caring for child as a dependent that isn't their own.*
- *I'd like to see it acknowledged that not all Carers live with the person being cared for.*
- *Include anyone who is providing unpaid care for a child or adult not in their family (even if it is voluntary or informal kinship care).*
- *As a grandparent we get no help we live week to week to give the kids what they need and we most times go without, in order for them to have what they need we raise [number withheld] grandkids with no help. We don't even have enough to repair cars I have gone through cancer treatment ... its time we as grandparents get paid and recognised.*
- *Add care for people who have not been recognised as having a disability eg ADHD but have a huge impact on life.*
- *I think it should say something like "Anyone who cares for another person or persons in any way to assist them with everyday, personal, legal, financial, medical and any other thing as required by that person/s specific needs or requirements/capacity. This may be assisting people to understand eg legal or medical needs, information or as required to assist that person/s. It may be advising medical staff in hospital about specific needs, medical requirements, mental health or other issues to make sure the person/s receive the very best assistance, medications, care and help they need. "*
- *A Carer is a person who provides personal care, support and assistance, pays bills, deals with home repairs, buys clothes, does weekly food shopping, provides transport, attends medical appointments, organises Webster packs [medication support] and is available 24/7 to provide counseling and support.*

Carers SA believes there is opportunity to consider redefining the Act's definition of a Carer based on the dynamics related to the caring role, defining a Carer in relation to assistance or services needed and provided that are above generally comparable needs – and not purely based on a medical diagnosis as is currently the case.

A medical diagnosis is often a key indicator of potentially presenting care needs, but on its own it does not necessarily determine a person's need for support with daily activities of life or informed decision making.

Furthermore, focussing Carer definitions on listings based on population, communities or caring role types is likely to be rather extensive (and confusing), but also a rigid description of the South Australian Carer population. As the Act will set the relationship between Carers and agencies and services under the Act for many years to come, it is important that the descriptions set in the Act provide clarity of intent, yet are flexible enough to accommodate changing environmental influences, altered community needs and expectations in its translation into practice.

Practical support is currently provided to people who fit a far broader definition of Carers than the current narrow definition provided within the Act.

The current definitions of a Carer within the Act require clarification based on intensive work and consultation with key stakeholders. The definition below will serve as a starting point for further evaluation and discussion.

A Carer is a natural person who provides ongoing personal care, support and/or assistance to a family member or friend that is above and beyond that expected by society in that relationship.

Carers SA also suggests that important clarity around the definition of a Carer under the Act can be achieved further by clearly stating exclusions under the Act.

Currently these exclusions are under Section 5:

(2) A person is not a carer if the person provides the care or assistance—

(a) under a contract for services or a contract of service; or

(b) in the course of doing community work organised by a community organisation within the meaning of the Volunteers Protection Act 2001.

(3) A person is not a carer for the purposes of this Act only because the person—

(a) is a spouse, domestic partner, parent or guardian of the person to whom the care or assistance is being provided; or

(b) provides care to a child who has been placed in the care of that person under the Children's Protection Act 1993, the Children and Young People (Safety) Act 2017 or any other Act.

Feedback from Carers indicates that the point 5.(3) could benefit from some clarification. For example: The description that a person is ***not a Carer only*** because the person is a spouse etc (under point a.) or a foster or kinship Carer (under point b.) has been causing confusion for many Carers.

We are aware from Carer and community feedback that, the exclusion intention behind the word '**only**' has the **unintended consequence** that Carers who identify as being within relationships under 5. (a) and (b) assume that they are actually excluded under the Act.

The implied additional need for support with daily activities in addition to the generally expected mutual support provided within a relationship of that kind in order to be recognised as a Carer under the Act- **is often missed.**

The definition of a Carer as well as the exclusion definitions must be seen as integral to one another and must therefore be read together, in order to ensure the application of the intentions of the Act into everyday life for Carers.

It is therefore most important that based on consultations with key stakeholder, a harmonisation of the definition of Carers with exclusion definitions is achieved.

Design and Decide with Carers – not for Carers.

For over three decades Carers SA has always received the richest insights, ideas, and suggestions about Carers from direct and open conversations with Carers. It is because of this that Carers SA intensively consults with Carers across South Australia.

Given the opportunity, Carers openly share a rich tapestry of their experiences as Carers, and detail insights, concerns and suggestions regarding support needs, services, policy and advocacy across sectors, services, and Government agencies that are touchpoints for Carers.

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- *'I feel undervalued with little acknowledgment by government or the local community.'*
 - *'As a carer, I do not feel valued by the government.'*

Examples of Carers' Comments

The official Review Consultations with Carers only allowed for one single metropolitan public consultation event for Carers. As mentioned, it is our experience that rich insights, ideas and suggestions regarding support and Recognition for Carers come during direct and open conversations with Carers. Carers SA would have hoped for broader consultation, that would have included regional South Australia, to ensure a representative cross section of Carers voices were being heard for this most important 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.

Carers recommend a true consultative and co-design approach in partnership with Carers be initiated to ensure a stronger trust relationship between Carers and State and Local Governments.

Active Translation of the Act into Practice

Half of the Carers in the National Carer Survey⁹ are telling us that they consider their experience with Government as sub-par with regards to Recognition as Carers. Interactions are often experienced as a rather passive approach to Carer Recognition. A passive approach to implementing legislation or guidelines is not congruent with the core intentions of any Act or formal Recognition Statement.

It cannot be that the onus is on Carers to elicit Carer Recognition and demand adherence to the Act's intentions and the principles in the Carers Charter to receive information and system navigation support.

An active approach to identifying Carers is specifically important for Government Departments and services that are key touch points for Carers, and employers of staff and volunteers with caring responsibilities.

Such an active approach to Carer Recognition may also address some of the issues around self-identification as a Carer (hidden Carers). Lack of self-identification is an issue in culturally diverse communities, where the concept of caring as a status or role is not differentiated from expected inter-family and inter-generational support or other implied roles. Quite often we hear statements from Carers, like: *'I am not a Carer, I am just looking after my... [mum/dad, husband/wife, child/ren, sibling or friend]'*.

⁹ National Carer Survey 2020 data available online: [Summary_Report.pdf \(carersnsw.org.au\)](https://www.carersnsw.org.au/summary-report)

Lack of self-identification restricts help seeking behaviour and in turn stops Carers from seeking and accessing Carer services until a point of crisis has been reached. We are also aware that recognising one's role as a Carer can be of assistance with the caring role itself when navigating medical or health / mental health services, aged care or disability services.

Due to this, an active translation of the Act into practice has the added benefit of eliciting early identification of hidden Carers and encouraging early help seeking behaviour by Carers. This allows Carers to be identified as a Partner in Care early in the service relationship and ensures their Recognition as a valued contributor to community.

'Carers should be considered as partners with other care providers - this has not been my experience with my adult children who were unable to make decisions for themselves due to severe mental illness, and even with their consent, I as the parent was not included in many decisions and I feel this has at times significantly impacted on the care they have received and outcomes.'

Carer Comment

Examples: Active Approach to Carer Recognition

Young Carers in Education

In a recent Carer Recognition Focus Group for Young Carers, a student told us that she had to fight for Recognition of her status as a Young Carer at her school. There are at least 2-3 Young Carers in the average South Australian classroom and at this particular school the staff were not aware of any Young Carers.

The young person strongly advocated for the Recognition of Young Carers at the school by approaching the School Counsellor with concerns that Young Carers may not achieve their full educational potential due to their caring role. According to the Young Carer, the school took some internal steps to identify other Young Carers – which resulted in an immediate identification and referral of 15 Young Carers from that school to specialist Young Carer support services. It would be important that these localised steps taken by some schools become a systemic strategy for all agencies under the Act.

Carers within the Health System

There has been an increase in the Recognition of Carers within the SA Health systems and Local Health Networks. SA Health has consulted strategically with Carers SA on Carer Recognition Strategies since 2015. A practical outcome of that work has occurred within the hospital admission process where SA Health introduced an option to ask a presenting patient whether they have a Carer, or whether they are a Carer themselves.

This is an excellent example of supporting systemic Carer Recognition that directly impacts practices that recognise Carers as Partners in Care when they are supporting a patient. Asking and recording these questions may also directly influence the patient care for Carers who become patients in a hospital. The question becomes especially important when Carers care for people who need ongoing support, supervision or alternative care arrangements whilst the Carer is a patient. If the question is not asked and that need is not identified the health and wellbeing of the person receiving care at home could be at risk.

There have been a number of occasions when identifying a Carer and the caring role at the point of presentation at a hospital led to the referral of the Carer to Carers SA and the arrangement of early support interventions such as emergency respite. This supports the person who is generally in the care of the Carer, but it also eases the stress and worry of the Carer who is now a patient in his/her own right.

Unfortunately, to the best of our knowledge the Carer related questions are currently not compulsory for staff to ask.

Embedding a reporting requirement detailing active approaches to identify Carers that are taken by agencies under the Act would encourage better strategic processes.

A South Australian Carer Strategy would be able to support this requirement by detailing the requirement further. For example: annual reporting of the number of identified Carers accessing services which in the above examples would provide the number of Carers accessing health services and the number of Young Carers identified at schools. This would be an important step for

better Recognition of Carers and allow the Act to be translated into everyday practice. It would assist authorities under the Act and their agencies to identify Carers and follow the Recognition intentions set by the Act.

Reporting and Reviews

To ensure the Recognition and wellbeing of Carers is paramount, it is vital there is an obligation to have checks and balances in place to monitor the translation of the Act's intentions into practice.

This includes:

- Appropriate reporting requirements that are meaningful and represent a true measure of Carer Recognition practices, as well as
- A formal feedback mechanism set in place to allow complaints and compliments to support reflection, outcome evaluation and future ongoing improvement strategies.
- Ongoing improvement strategies extend to an inbuilt timeline for regular reviews of the Act itself.
- The Act should include the requirement for a Carer Recognition Plan within a South Australian Carer Strategy to support authorities under the Act with the implementation of the intentions of the Act, with regular reporting and inbuilt Plan reviews – similar to the content of the South Australian Disability Inclusion Act 2018¹⁰.

Feedback from those most impacted by the Act is a key component for any appropriate evaluation and ongoing assessment of the effectiveness of the Act.

In the Carer SA's Carer Recognition Survey 2023, an astonishing 70% of Carers were not confident to provide feedback and raise a concern or lodge a complaint as a Carer about a Government agency.

It is also very difficult for a Carer to identify where complaints or comments can be lodged – and often depends mainly on the type of service that the person(s) receiving care is accessing. Complaints can be lodged with service agencies that provide the services related to the person receiving care about that service. Some existing complaint pathways can therefore exclude complaints from Carers about issues Carers face as Carers. Generally, Carers more often than not, find it difficult to identify the appropriate Advocate to escalate an issue beyond a direct approach to the service provider, or Government Department.

Trying to lodge a complaint can be a journey of many wrong doors across departments¹¹ for Carers.

Carers provided feedback to Carers SA that they would prefer a single contact point where a complaint could be lodged – and importantly where support could be accessed to go through the process of lodging a complaint.

Here are some examples of the 220 Carer comments we received on the topic of confidence to provide feedback such as raising a concern or lodging a complaint:

- *When I wanted to express my concerns about my daughter's care in a psych ward it was very difficult to find an avenue to express my bad experiences.*
- *There is no independent complaints process.*
- *Online options for complaints etc so can be done in free time, rather than dealing with long hold times etc.*
- *Most departments or agencies have detailed written information on how to complain.*

¹⁰ [Disability Inclusion Act 2018 | South Australian Legislation](https://www.legislation.sa.gov.au/lz/path=%2FC%2FA%2FDisability%20Inclusion%20Act%202018) accessible online via:

<https://www.legislation.sa.gov.au/lz/path=%2FC%2FA%2FDisability%20Inclusion%20Act%202018>

¹¹ See SA Government's Complaints and Advocacy Advice for Carers via <https://www.sa.gov.au/topics/care-and-support/carers/complaints-and-advocacy>

South Australian Carer Strategy

Carers SA supports the development of a South Australian Carer Strategy with an integrated Carer Recognition Plan to support the overarching principles and intentions of the Act. It is strongly recommended that this SA Carer Strategy be embedded in the Act.

The purpose of the Strategy and incorporated Plan would be to:

- Support authorities under the Act and their agencies to develop appropriate Carer Recognition Strategies and fulfill their obligation under the Act.
- Further clarify expectations and obligations under the Act.
- Provide guidance on outcome timeframes and reporting expectations.
- Establish review timelines.

Ensure Stakeholder Engagement and Strategic Partnership

- A requirement for a Strategy being built into the Act would provide options to adjust approaches and planning to answer the general changes within society and community expectations that impact Carers, for example South Australia has a higher number of ageing Carers due to an ageing population.
- Therefore, a significant amount of flexibility is needed to answer the changing needs of Carers based on population dynamics and changing environments.

Although there are key commonalities in the experiences all Carers share, there are very individual differences in what Carers need based on:

- Individual circumstances and caring roles,
- Whether a Carer resides in the metropolitan area, regional or remote, or
- Whether Carers identify with a specific community.

For example: First Nations, culturally or linguistically diverse communities, LGBTIQ+, Youth, Seniors, Carers juggling caring and employment and other groups.

A South Australian Carer Strategy and subsequent Plan will give opportunity to appropriately address Carer Recognition dynamics across populations, locations and needs across specific populations of Carers.

Here are examples that may provide insight into the Carer Recognition complexities across just two of the mentioned Carer populations:

Recognition of Young Carers

Recently, Carers SA conducted a Carer Recognition focus group with Young Carers from varied backgrounds and schools.

Here are some of the points Young Carers raised, that demonstrated their experiences with Recognition:

Education

- *There needs to be more education for people to improve the understanding around young people in a caring role. Hardly anyone knows about what does this actually mean day to day for them.*
- *There is a need for Education Department to identify and recognize Young Carer roles in school and how they are impacted – how it affects their capacity to engage in school.*
- *Schools do not ask if they are in a caring role (on enrolment or at all). When I help my brothers go to school they acknowledge me as a sister only.*

- *Study and access to secondary education; there needs to be greater support and accessibility. What options are there for subsidized learning, flexible learning, reduced school and TAFE fees for Young Carers?*
- *“Young Carers” is a taboo subject; have had to fight to be recognized at school. Additionally, there is a lack of awareness around disability – need for education and inclusivity.*
- *Advocacy – feels consistently in an advocacy role not only for people we care for but also for myself as a Young Carer.*
- *Transport to and from school; needs more support for YC’s to get to and from school / school scheme is not enough – doesn’t recognize when students can’t get to and from school within 5 km.*

GP / Allied Health

- When they see my family, they see me.
- GPs don’t ask about my role, my wellbeing.
- Do not feel seen.
- *Going out in the community or escorting to doctor's appointments, hospitals, and shopping centres can be hard due to not enough accessible parking [disability parking / safe drop of / pick up areas] – which can result in fines when parking where I should not, to assure Mum can safely reach the car on pick up. There should also be reduction in fees.*

Financial

- *Need more guidance and awareness around what support is available for example information about concessions and Centrelink payments.*
- *Money is getting tighter and tighter for families – it makes it harder for Young Carers too.*
- *Barriers are created for people who are both caring and have a disability themselves. Services require you to be one or the other – not both – including with concessions.*

It is evident that there is extensive scope to improve the translation of the Act’s intentions focussed on consultation, service and support provision, and general Recognition of Young Carers across several authorities under the current Act.

A strengthening of the language about Young Carers and a raising of awareness of the Act and its expectations on authorities and their agencies under the Act is key to effective translations into practice.

In 2020, the South Australian Commissioner for Children and Young People published the South Australian Commissioner for Children and Young People, 2020, *“Take Care” Report: What can be done at school to support children and young people with caring responsibilities at home*¹². This report’s recommendations can serve as a resource for planning the translation of the Act’s Young Carer related stipulations into practice within South Australian schools and TAFESA.

Carers SA further suggests a cross departmental and evidenced approach to designing service and support for Young Carers across South Australia. This should involve key stakeholders including Young Carers, Carers SA and the Youth Affairs Council of SA resulting in a more effective and efficient strategy to improve the education, employment and financial security outcomes for Young Carers.

¹² South Australian Commissioner for Children and Young People, 2020, “Take Care Report: What can be done at school to support children and young people with caring responsibilities at home” <https://www.cyp.com.au/wp-content/uploads/2020/07/Screen-Take-Care-Report-4.pdf>

Recognition of Older Carers

The 2018 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) estimated there were 647,000 older people (aged 65 and over) providing care. Older Carers represented around 1 in 6 (17%) of the total older population and just over half (51%) of older Carers had a disability. In younger age groups the majority of Carers are women, however, this changes quickly for older Carer age groups. 57.7% of Carers who are 75-84 years of age are men and nearly 3 in 4 (71.9%) Carers 85 years and older are men¹³. According to the SDAC, of all older informal Carers, over 1 in 3 were primary Carers (that is, the Carer providing the most informal assistance to a person). Around 6 in 10 older primary Carers were women. Of these older women who were primary Carers, 7 in 10 (71%) provided care to their partner, 13% provided care to their child, and 11% provided care to their parent. A rising number of older Carers are taking on caring roles for grandchildren with additional needs.

Older Carers are the only group in our community who cannot retire.

Older unpaid Carers face various challenges and impacts on their health, and social and emotional well-being, such as stress, anxiety, isolation, depression, and physical strain¹⁴.

Older Carers have special support requirements that may differ from that of younger Carer groups, such as Recognition, respect, respite, information, advocacy, financial assistance, care-related services, peer support, counselling, coaching, and skills courses. For those older Carers who have not yet reached retirement age (currently, 67 years) this may require supporting job redesign¹⁵.

Carers who are 65+ years old are less likely to ask for assistance compared to those in younger age brackets. It is therefore specifically important to ensure that authorities under the Act are actively identifying people who have Carer status and provide appropriate services, information and referrals.

Older Carers are a distinct group with specific needs. This group requires additional considerations, assessment, and services based on capacity to safeguard their wellbeing and health.

Some comments we heard from older Carers in surveys and conversations:

- *We thought we would be retiring by now and looking after ourselves as we are no longer as strong as we used to be. Our health is getting worse, even everyday tasks are getting harder and then there is the caring role on top.*
- *I am just barely coping.*
- *Everything is getting so much harder.*
- *It is hard to keep up with computers – but everything is online now.*
- *... and so stressed out about all the tasks I have to do, I often don't know whether I am 'Arthur or Martha'.*
- *I really don't know how much longer I can do this, but who will do it then?*
- *I need help for myself.*
- *I don't feel safe.*

¹³ Australian Institute of Health and Welfare, Older Australians Report available online:

<https://www.aihw.gov.au/reports/older-people/older-australians/contents/social-support>

¹⁴ BMJ Open Health Policy, *What are the consequences of caring for older people and what interventions are effective for supporting unpaid carers? A rapid review of systematic reviews*. Available online:

<https://bmjopen.bmj.com/content/11/9/e046187>

¹⁵ Human Rights Commission, *Recognising and Valuing Unpaid Care*, available online:

<https://humanrights.gov.au/about/news/speeches/recognising-and-valuing-unpaid-care>

Summary of Carer SA's Carer Recognition Experience Survey

Carers SA conducted a Recognition experience survey and **689 Carers** participated sharing their experiences about the practicalities of Carer Recognition.

The project also involved the members of the CSNSA as well as several key partner organisations who supported the distribution of the information to Carers.

The survey data is included in the following section to provide the Review with direct access to the views of Carers with lived experience insights regarding the Recognition of Carers across South Australia.

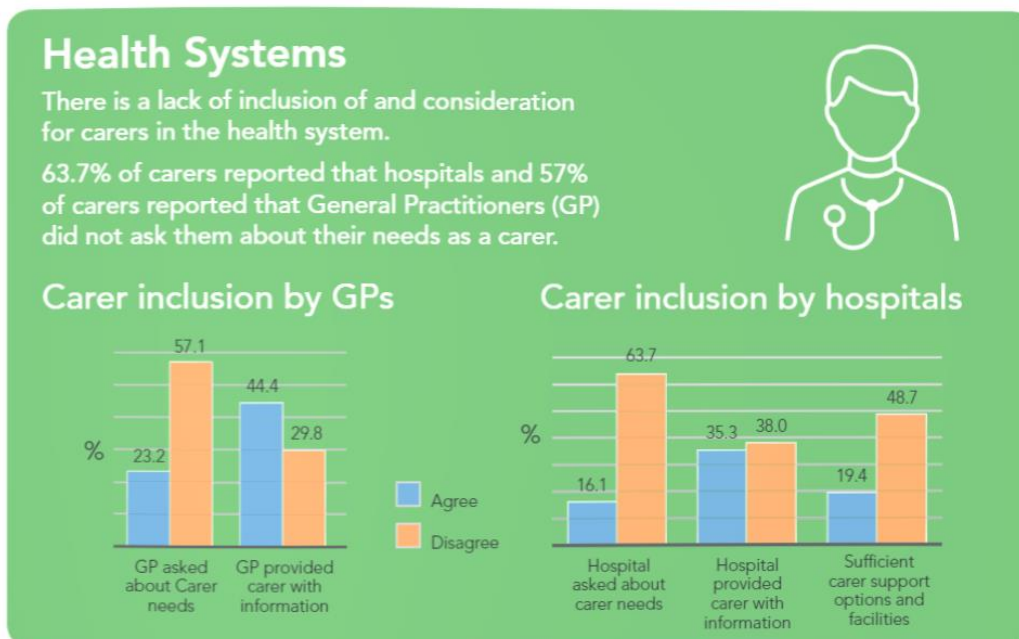
Some of the details Carers told us in the Carers SA Carer Recognition Survey 2023 is also reinforced by the data from the National Carer Surveys 2020 and 2022 and is identified where applicable.

Carer SA Carer Recognition Survey 2023 – Participant Demographics at a glance

- 2.42% of participants identified as members of Australia's First Nations Peoples (Aboriginal / Torres Strait Islander).
- 4.4% identified as members of the LGBTIQ+ community.
- 6.2% speak a language other than English, unless they needed to.
- 6.4% stated that a person they provide care for is mainly speaking a language other than English.
- 32% of participating Carers are caring for two (2) or more persons.
- Age of Carers was between 16 and 80+
 - 49% aged 45-64,
 - 60% of participating Carers from linguistic diverse families were aged 45-60.
- 2/3 Carers lived in the metropolitan area, 1/3 lived in country and remote South Australia.

National Carer Survey– SA data regarding Carer Recognition within SA’s Health system.

Below is an example of the Carer Recognition status within the South Australian health system collated via the 2020 National Carer Survey – SA Analysis.



Carer comments examples:

Intake Process

- *At a time when my husband was taken by ambulance to hospital, I followed in my car, the triage nurse would not let me into the treatment area, even though I said my husband had dementia and could not answer medical questions, the ambulance officer took me in. The nursing triage staff have no idea of my husband’s needs and his need for me, as he was crying for me. That is why the ambulance officer came looking for me. That was lucky..*

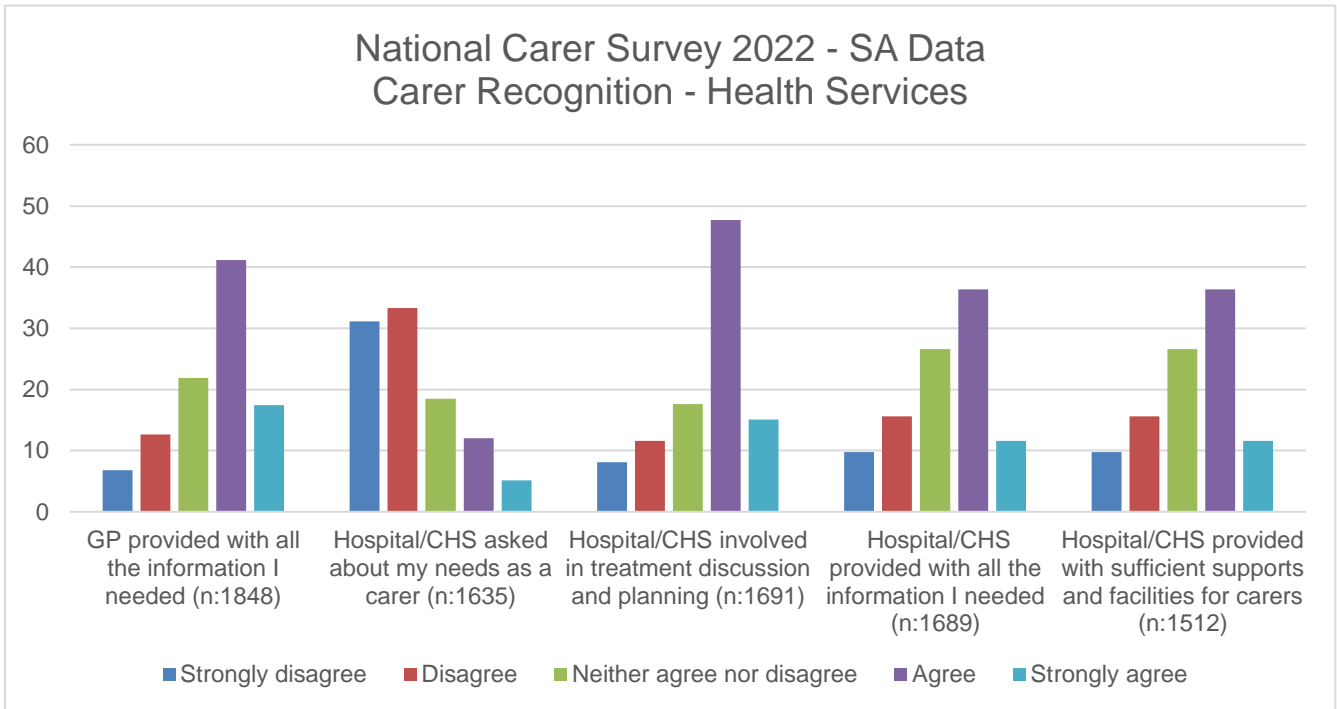
Discharge Process:

- *Disappointed with some aspects of the RAH, still waiting for official discharge report.*
- *Discharge planning is always a problem in public hospitals.*

An analysis of the South Australian data collected during the 2022 National Carer Survey (unpublished) provides indications of some positive improvements but confirms persisting shortcomings into transitioning well-meaning intentions of the current Act into discernible practice.

As the graph below demonstrates the highest ratings achieved across settings was 62.8% of Carers who recalled being involved in treatment discussions and planning in SA hospitals and Community Health services. In other words, only 62.8% of Carers are involved in key discussions that are vital for the person they care for.

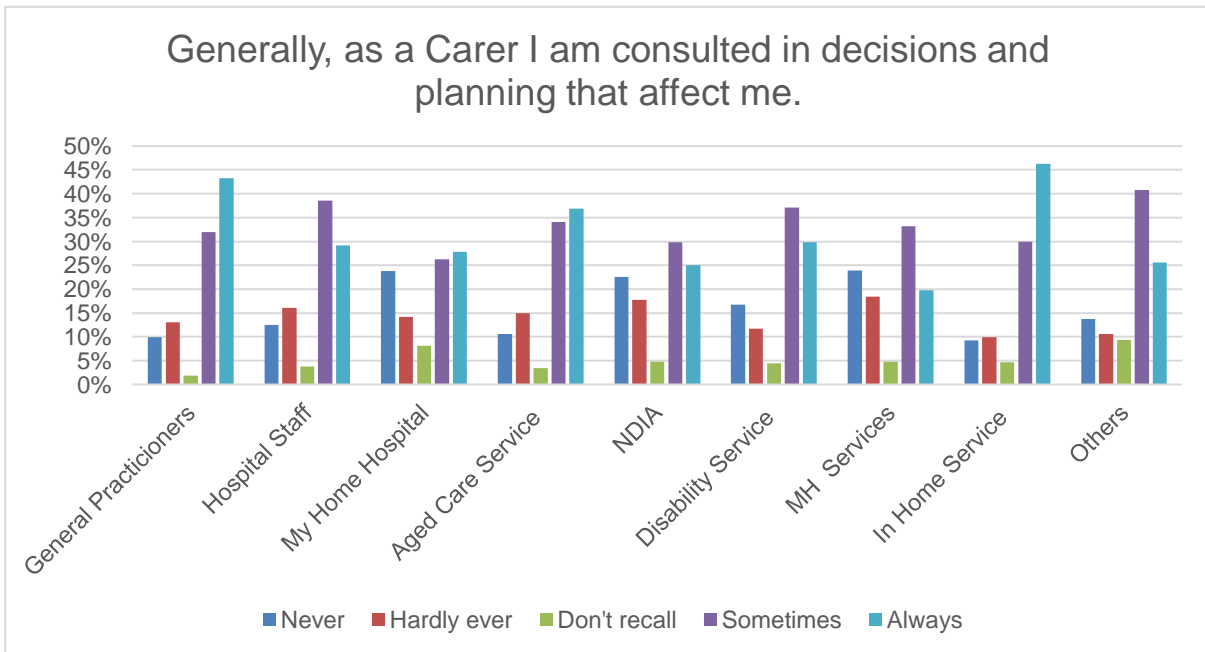
National Carer Survey 2022 - SA Data Carer Recognition - Health Services



Carer Recognition by key Government / Agencies with direct impact on Carers' lives:

We asked Carers to recall how well health related service providers consult in decisions and planning activities that have an impact on the Carer. Of those Carers who accessed the services, only 65% reported that they were sometimes or always consulted in processes that impacted Carers. In addition to these, nearly a third of Carers (30%) were hardly ever or never consulted despite any potential impact on the Carer. Hospital staff across South Australia consulted more often with Carers (68%) than staff involved in My Home Hospital services (54%).

See the graph below:

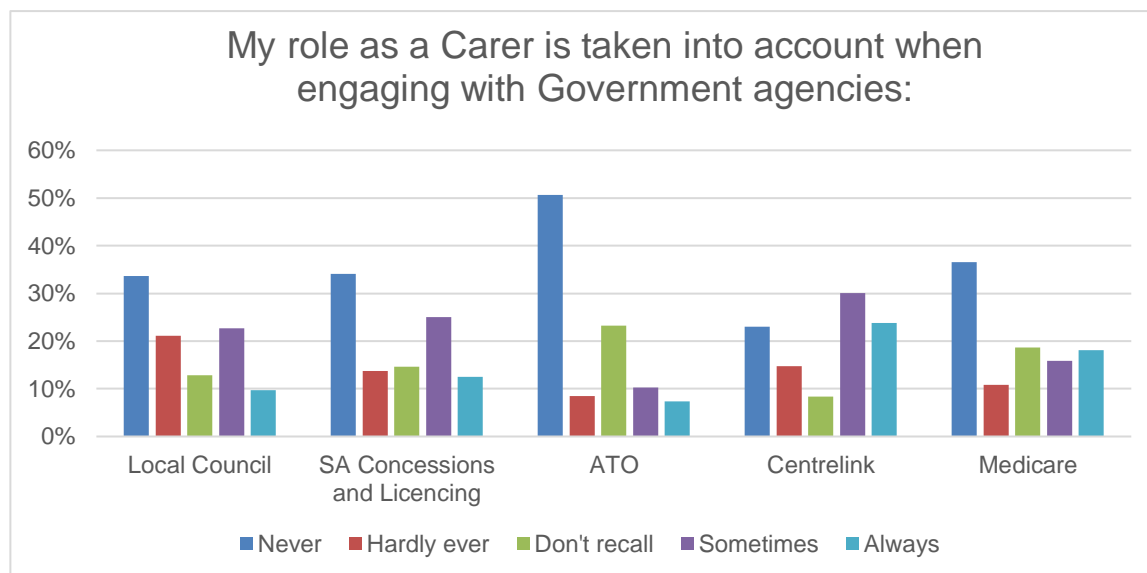


One of the issues identified: Discrimination.

- 28.6% of survey participants disclosed that they have experienced discrimination during their interactions with Government in general (including health and related services).

- This percentage is significantly higher for members of Australia's First Nations Peoples at 44%.

We asked Carers whether their role as a Carer is taken into account when dealing with some of the key Government Agencies (other than health related services) that connect with Carers: Local Council, SA Concession and Licencing, and some comparison experiences for federal Government departments and services: Australian Tax Office (ATO), Centrelink (Services Australia) and Medicare. Centrelink was the only Government agency where more than half (54%) of the Carers could recall a Recognition of their caring role.



Due to a lack of appropriate Recognition and engagement (often may be due to workloads and empathy fatigue) it is therefore not surprising that over time, unintended institutionalised barriers to communication and respectful human interactions have developed. Two key barriers of concern identified by Carers are:

- Government Language:
 - 29.5% of Carers told us that they feel uncomfortable when they have to work with 'Government Language'.
 - This number is significantly higher for Carers identifying as members of the LGBTIQ+ community at 41.4%.
- Discrimination:
 - 28.6% of survey participants disclosed that they have experienced discrimination during their interactions with Government (including health and related services).
 - This percentage is significantly higher for members of Australia's First Nations Peoples at 44%.

Examples of Carer comments we received:

- *I'm overwhelmed mentally and need things explained in simple terms. I don't want to find out about some loophole that stops me or the people I care for from getting help.*
- *Most institutions have poor systems for dealing with 'third parties' that have legal authority to act on behalf of a person with impaired decision making.*
- *The government agencies do not respect or recognize the Carer's personal life, goals and aspirations and work commitments and importance of maintaining a healthy life style.*

- *[...] seems to think all Indigenous people are drunks.*
- *We have lost all our basic human rights since coming to Australia – the discrimination and racism we face daily is disgusting!*
- *I can't recall feeling discriminated against when dealing with a government, but I have felt that they didn't care or didn't understand the circumstances and a lack of logic.*