



Name: Carers NSW

Submission date: 13/06/2025

Participant background

1. For the purposes of this consultation, which of the following best describes you:

I am an industry or advocacy organisation, professional association or peak body

2. Which of the following care sectors will your feedback relate to? Please select all that apply.

Aged care; Carer services and supports; Disability; Health; Veterans

3. What kind of care supports, services and programs do you have experience with, and in what jurisdictions?

The participant did not respond to this question.

1. Reform of quality and safety regulation to support a more cohesive care economy

1. To what extent do differences in quality and safety regulation make it costly or complex to provide or access care services?

Somewhat

2. What are the reasons for your answer?

Carers NSW has previously raised concerns with the Australian Government about the impact of the differences in quality and safety regulations across the care and support sector, especially in thin markets (rural, regional and remote markets, specialist services markets). Having multiple, non-aligned regulatory models may act as a disincentive to providers operating across sectors, growing the market, even where they are capable of doing so. This is because:

- It may be costly to providers to undertake multiple quality audits, especially where the onus is on providers to meet these costs.
- It may increase the administrative work for providers to ensure they are fulfilling requirements under multiple systems.
- It may make it difficult to establish good clinical governance, especially where regulatory models are contradictory
- It may also make it difficult for staff to work across sectors, there may be confusion about differing quality and safety expectations or requirements across different service systems.

For carers, who are often caring for more than one person or also accessing services on their own behalf, differences in regulatory approaches across the care and support sector may make it difficult to understand the standards and quality of care that they can expect within different services systems. For example, someone caring for an ageing parent receiving aged care services and spouse living with disability accessing the National Disability Insurance Scheme (NDIS). This can make it challenging for carers and the people they care for to undertake due diligence or monitor or respond to the quality of services and supports.

Furthermore, within the context of regulatory alignment, as well as Australian care and support policy more broadly, Carers NSW also believes that it is imperative that carer supports are considered and included within discussions regarding the care and support sector. Carers NSW has been deeply concerned that despite the investment in the establishment of Carer Gateway - a national service system for carers, complementary of the NDIS and My Aged Care - carer supports continue to be overlooked in initiatives aimed at improving alignment and cohesion across the care and support sector. Carer Gateway provides similar supports to those available through other care and support systems, including practical supports such as domestic assistance, home and community respite, residential respite, clinical services and transport. As such, Carer Gateway may draw on the same pool of providers and workers as other systems across the care and support sector, however this is often not accounted for in planning and design of workforce, market and regulatory planning and policy, which is likely to undermine the effectiveness and efficiencies of the sector as a whole.

Carers NSW has previously raised these concerns in greater detail in submissions responding to the Department of Health and Aged Care Aligning Regulation across the Care and Support Sector initiatives and to Prime Minister and Cabinet draft National Care and Support Economy Strategy which are attached to this response.

3. [To what extent should quality and safety regulations be more aligned across the different care service sectors and jurisdictions?](#)

To a great extent

4. [What are the reasons for your answer?](#)

Carers NSW has advocated for many years for greater regulatory alignment across the care sector and has worked closely at times with the Department of Health and Aged Care to inform the work of the Regulatory Alignment Taskforce.

While Carers NSW has strongly advocated through current reforms of regulatory models in aged care and the NDIS, Carers NSW is concerned that this pivotal junction, in which both service systems were under review concurrently have been a missed opportunity. Carers NSW acknowledges the work done to align the aged care Code of Conduct with the NDIS Code of Conduct, however a number of opportunities remain. This includes aligning the number of registration categories and what these levels encapsulate across the aged care and disability sector, improving information sharing between quality and safety bodies and establishing one national worker screening program across the broader care and support sector.

Carers NSW acknowledges that there must be opportunities for a nuanced approach that enables the differences between service sectors and care recipient groups to be appropriately addressed, however we also believe that streamlining regulation across all parts of the direct care and support sector will have a positive impact for all Australians who require care, and the family and friend carers who support them.

2. Embed collaborative commissioning to increase the integration of care services

1. What is your experience with collaborative commissioning

The participant did not respond to this question.

2. What are the benefits of pursuing greater collaborative commissioning?

The participant did not respond to this question.

3. What are the barriers to collaborative commissioning, and do you have any suggestions for solutions that would lead to better collaboration in the commissioning of care services?

The participant did not respond to this question.

3. A national framework to support government investment in prevention

1. What are the main barriers to governments investing in evidence-based prevention programs across the care economy?

Please see response below for feedback on investment in prevention.

2. What are some examples of successful prevention programs (this could include discontinued programs)?

N/A

3. How can governments better support investment in prevention activities that have broad and long-term benefits for the Australian community?

Many initiatives aimed at prevention are often time-limited and or intended to be one off, however, prevention may also require an approach that provides ongoing low-level services. Providing ongoing low-level support long-term may prevent or reduce the need for moderate or intensive services, which will benefit people accessing these services, while also reducing costs.

For example, carers may benefit from ongoing access to planned respite or replacement care to enable them to take breaks from the caring role to support their mental health and wellbeing, as well as their social and economic participation. Given the benefits of respite to carer mental health and wellbeing, it is also likely that ongoing access to planned respite will reduce psychological distress amongst carers, support the sustainability of caring arrangements, reduce reliance on formal care systems and reduce the need for costly crisis intervention. However, Carer Gateway, the national service system for carers, while providing important short-term support, including respite, aimed at improving carer mental health and wellbeing, is unable to meet the ongoing maintenance needs of carers as it is not intended to be a long-term model of support.

While it is expected that other service systems will complement Carer Gateway to meet ongoing respite needs, many carers provide support to someone who is ineligible for aged care or NDIS services and there are limited alternatives outside of these formal service systems in NSW. Therefore, Carers NSW believes that ongoing access to low-level supports are a key element of prevention for many carers.

Cover sheet: Supporting document #1

3 July 2023

Department of the Prime Minister and Cabinet
PO Box 6500
Canberra ACT 2600
CareandSupportEconomyTaskforce@pmc.gov.au

Draft National Care and Support Economy Strategy

Carers NSW thanks the Department of the Prime Minister and Cabinet (the Department) for the opportunity to provide feedback on the Draft National Strategy for the Care and Support Economy (the Strategy). Carers NSW commends the Department on taking an holistic approach to addressing challenges facing the care and support economy and for taking a carer-inclusive approach in their response. This submission will highlight the need to include the carer support sector in discussions and initiatives relating to the care and support economy. The submission will also outline opportunities to streamline pathways to employment in the care and support sector for family and friend carers who are interested in entering employment in this sector.

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

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

Thank you for accepting our submission. For further information, please contact Melissa Docker, Senior Policy and Development Officer at melissad@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW believes in the importance of autonomy and self-determination for people who receive care and support from others, and is supportive of policy and practice that facilitates their independence and meaningful participation in community life. Additionally, Carers NSW recognises that not all people who receive formal or informal support would identify as having a 'carer'. However, family members and friends are important in the lives of all Australians, and the Australian Bureau of Statistics (ABS) reports that the majority of Australians who need regular assistance receive at least some of that assistance from a family member or friend.¹

Carers NSW commends the Australian Government for approaching the care and support economy holistically, as many providers and individuals operate and work across multiple care and support systems. For family and friend carers, engagement across multiple service systems is also not uncommon, particularly for those who have multiple caring roles, or if they have a disability or long-term illness themselves. Carers NSW has previously advocated for taking a more integrated approach to addressing challenges related to the care and support economy such as market and workforce shortages, as these challenges often transcend service systems.

Recognition of the experiences and needs of carers within the care and support economy

Carers NSW commends the Department for recognising the need to value the contribution of informal carers and to support them to sustain their caring roles in Objective 1.6. The Australian Bureau of Statistics (ABS)² estimates that there are approximately 2.65 million family and friend carers across Australia, including approximately 861,000 primary carers. While many carers choose to provide informal care and report positive aspects of the caring role, caring can often have significant negative impacts on carer health and wellbeing, as well as their social and economic outcomes. These impacts are exacerbated when carers are unable to access adequate support to sustain their caring role.

Carers NSW has continued to raise concerns that the shift to person-centred models of care, while important for furthering the autonomy and rights of individuals accessing formal care services, has created an unintentional reduction of focus on the experiences and needs of family and friend carers.³ Carers NSW is pleased that the Department has acknowledged that ensuring support for family and friend carers is an element of providing person-centred care and not in contradiction of it.⁴ This involves better meeting the needs of people receiving care and support to enable sustainability of the caring role for carers, and also meeting the support needs of carers in their own right to enable them to achieve optimal health, wellbeing, and social and economic outcomes.

Carers NSW believes that in order to sustain their caring role, carers need timely access to formal care systems on behalf of themselves and the people they care for. Carers also need access to ongoing breaks from the caring role, more commonly referred to as respite, that enable them to prioritise their own health and wellbeing and participate in community activities. Additionally, inclusion of carers in

¹ Australian Bureau of Statistics (ABS) (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset, available online at: www.abs.gov.au.

² Ibid.

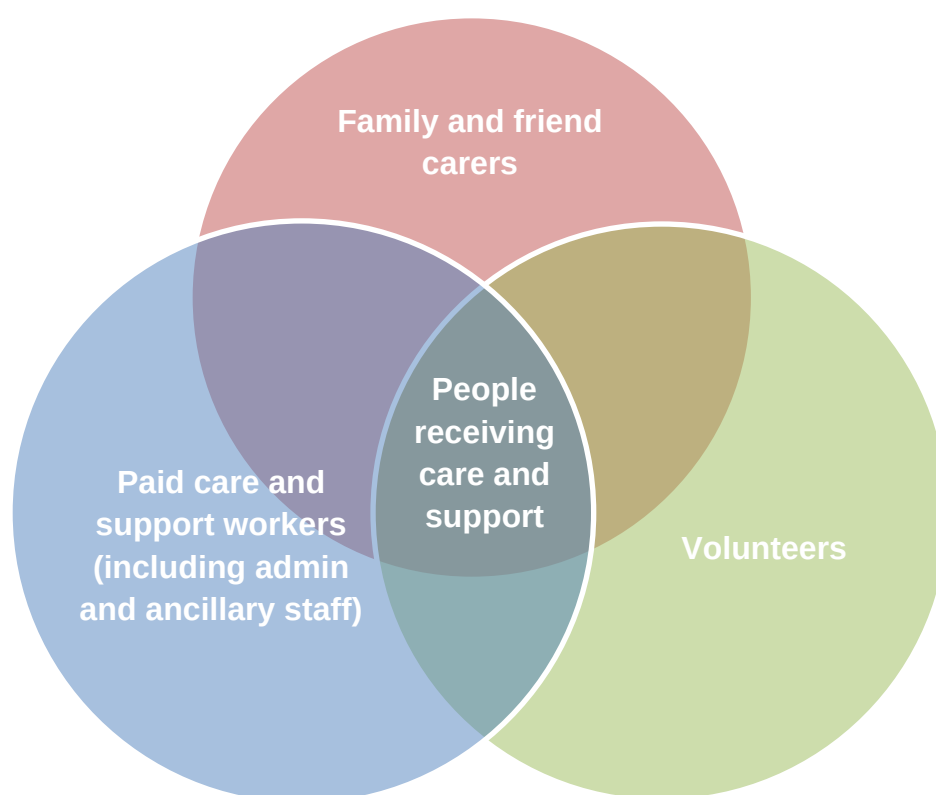
³ Carers NSW (2021) *Repositioning respite in consumer directed service systems*, available online at: <https://www.carersnsw.org.au/uploads/main/Files/5.About-us/News/Repositioning-respite-within-consumer-directed-service-systems.pdf>, viewed 30 June 2023.

⁴ Department of Prime Minister and Cabinet (DPC) (2023) *Draft National Care and Support Economy Strategy 2023: Care and Support Economy Taskforce (p.15)*, available online at: <https://www.pmc.gov.au/sites/default/files/resource/download/draft-national-care-and-support-economy-strategy-2023.pdf>, viewed 30 June 2023.

treatment or support planning and discussions and opportunities to identify carers needs' during assessment and planning is key to ensuring that carers needs' are identified and met.

Carers NSW is also pleased to see that informal care has been acknowledged as an element of the care and support economy in itself.⁵ Together, paid care and support workers, volunteers and family and friend carers enable the sustainability of formal care and support systems within Australia (Figure 1). In 2020, Deloitte Access Economics⁶ estimated that it would cost Governments across Australia \$77.9 billion to replace the care provided by informal carers each year, however this figure would likely be much higher from 2023 given the 15% aged care wage increase and broader indexation. Given the significant contribution of carers in the provision of care within the community, and the cost to governments if this care were to cease, Carers NSW believes that it is important to consider the roles and needs of informal carers within the care and support sector to ensure that they are adequately supported to sustain their invaluable roles within the community.

Figure 1. The interaction of different cohorts within the care and support economy



Carers NSW also believes that given the increasing complexity of care provided within the community, that carers should be adequately recognised and supported as of part of this workforce and receive the appropriate education and training to effectively provide this care. Access to formalised training that supports carers to provide safe and quality care in their home and community is likely to result in optimal outcomes for carers and the people they care for. Carers NSW currently offers Carer Skills Training for carers of people who are ageing, a 6-session training program that builds the skills and capacity of carers in relation to practical caring skills. However, the program is currently limited to particular cohorts.

⁵ DPC (2023), (p. 13).

⁶ Deloitte Access Economics (2020) *The economic value of informal care in Australia in 2020*, Carers Australia.

Inclusion of the carer support sector within the care and support economy

Carers NSW commends the Department for acknowledging the need for robust service systems and an adequate workforce and workforce mix to enable quality care and support. However, Carers NSW has previously raised concerns about carer support services not being considered or included in discussions and initiatives that aim to support the growth and development of the care and support sector. Carers NSW believes that any strategy that aims to address ongoing issues for the care and support economy must take into account the carer support service system, which works closely with, and often also draws on the workforce of, the aged care and disability service systems (Figure 2).

Figure 2. Carers NSW proposed care and support economy focus areas, inclusive of carer supports



Carer Gateway,⁷ funded by the Department of Social Services, now acts as the national service system for carers, funding a range of direct services and supports to both carers and the people that they care for. Carer Gateway Service Providers (CGSPs) directly provide, subcontract or broker care and support services in the home and community, including personal care, domestic assistance, transport, nursing, respite and social support for care recipients, enabling carers to access breaks from the caring role both in planned and emergency situations and sustain their caring role. Carer Gateway plays an essential role within the care and support sector, supplementing aged care, disability and health systems to enable increased support for carers to sustain their caring role. However, ongoing workforce shortages across the care and support economy, especially in regional, rural and remote areas have hindered the effectiveness of Carer Gateway to meet carer needs.

Carers NSW believes that the carer support sector must be included within the Care and Support Sector Economy strategy to ensure that it also takes into consideration the growing demands of Carer Gateway on the care and support economy as it continues to mature and that Objective 1.6 of the draft Strategy can be effectively achieved.

⁷ www.carergateway.gov.au

Enabling pathways into paid caring roles for family and friend carers

Family and friend carers seeking paid employment provide a unique opportunity to expand the formal care and support economy. Carers often have skills and experience in providing care and support to persons with additional needs in the community which can be transferred, with support, to paid caring roles where this is in line with their preferences. Additionally, carers are less likely than other Australians to already be in paid employment,⁸ often due to the impact of their caring role on their ability to work. However, paid employment in care and support roles can provide carers with greater flexibility and control of their work hours that may enable them to better balance care and work.

While Carers NSW evidence suggests that many carers are not interested in employment in the health and social care sector,⁹ some carers are. The 2018 SDAC indicated that 16.3% of carers and 20.7% of primary carers in NSW are employed in the health care and social assistance, compared to 13.3% of non-carers.¹⁰ For carers who are interested in employment in the care sector, programs which provide support with having caring experience formally recognised through Recognised Prior Learning (RPL) and developing specific qualifications that meet carers needs, have proven highly effective in supporting employment pathways for female carers. Carers NSW believes that ongoing focus on additional options for supporting carers to gain formal recognition for their skills developed through caring. This will also likely assist with addressing workforce shortages across the care sector, however should not be considered the solution to this issue.

Additionally, carers looking to enter the care and support workforce may also need financial support to address the costs of starting work in the sector such as first aid certificates and workplace checks (e.g. Working with Children's Check within NSW). Building the carer awareness and inclusiveness of employers within the care and support economy is also likely to enable them to better attract and support carers within the workplace.

Carers NSW is currently delivering a pilot project within NSW in partnership with Regional NSW which aims to address disability sector workforce shortages in regional areas by facilitating pathways to employment for young carers that acknowledges the skills and experience that they bring to the role and aims to overcome the unique barriers to work that carers face. Learnings from this project will aim to inform approaches to addressing barriers to work in the care and support sector for family and friend carers.

Furthermore, Carers NSW has also previously raised concerns about particular policies relating to income support payments for carers that may act as a financial disincentive for carers to enter employment. Low-income thresholds for Carer Payment recipients and the 25-hour rule¹¹ for carers receiving Carer Payment may act as a disincentive for carers to enter the workforce, especially if there is a chance that participating in employment, even at low levels, may jeopardise their already precarious financial position.

Carers NSW believes that the care and support economy strategy should include a focus on exploring opportunities to streamline pathways to employment and address barriers for carers who may be keen to enter the care and support workforce.

⁸ ABS (2019).

⁹ Carers NSW (2018) *2018 NSW Carers Survey*, available online at:

https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Carer-Survey-Report_2018.pdf, viewed 30 June 2023.

¹⁰ ABS (2019).

¹¹ Carers receiving Carer Payment are limited to participation in employment or education for a maximum of 25-hours per week (including travel time).

Conclusion

Carers NSW again thanks the Department for the opportunity to provide a response to the draft National Care and Support Economy Strategy. Carers NSW commends the Department on their recognition and inclusion of carers within the Strategy and believes that the proposed approach could be strengthened by including carer supports as part of the care and support sector and by exploring opportunities to support carers to enter the care and support economy where appropriate.

Cover sheet: Supporting document #2

17 December 2021

Department of Health
GPO Box 9848
Canberra ACT 2601
Australia

RegulatoryAlignmentTaskforce@Health.gov.au

Aligning Regulation across the Care and Support Sector

Carers NSW welcomes the opportunity to provide a submission to the Department of Health (the Department) on the aligning regulation across the care and support sector. Carers NSW supports the Australian Government's commitment to aligning regulation across the care and support sector as this is likely to allow for greater workforce and market growth. Carers NSW has also been active in advocating for the need to improve consistency and information sharing in the regulation of quality and safety measures across care service systems in order to improve quality and safety, simplify service navigation and streamline complaints and redress mechanisms.

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

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

For further information, please contact Melissa Docker, Senior Policy and Development Officer, on (02) 9280 4744 or melissad@carersnsw.org.au.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW commends the Australian Government's commitment to align regulation of Commonwealth-funded care and supports. Carers NSW has raised on a number of occasions the need to improve consistency and information sharing between regulatory measures across service systems to improve the quality and safety of care, support workforce growth and development, and to minimise the administrative burden often borne by carers navigating multiple systems (see Appendix A).

Carers NSW acknowledges that there must be opportunities for a nuanced approach that enables the differences between service sectors and care recipient groups to be appropriately addressed, however we also believe that streamlining regulation across all parts of the direct care and support sector will have a positive impact for all Australians who require care, and the family and friend carers who support them.

The 2018 Survey of Disability, Ageing and Carers (SDAC)¹ estimated that there are approximately 2.65 million carers in Australia who provide care and support to a family member or friend. Carers NSW acknowledges that not all Australians who require care or support receive this from an informal carer, however, many do.

This submission will highlight the benefits for carers of aligning regulation across the care and support sector, as well as the need to include carer support services (in particular, Carer Gateway) in the broader alignment process.

Considering the role of carer supports in the care and support sector

Carers NSW has previously raised the need to align regulation and compliance across the aged care and disability service systems in order to foster workforce growth and compliance with quality and safety measures. Carers NSW also believes that regulatory alignment must take into account the carer support service system, which works closely with, often also draws on the workforce of, the aged care and disability service systems.

Carer Gateway,² funded by the Department of Social Services, now acts as the national service system for carers, funding a range of direct services and supports to both carers and the people that they care for. Carer Gateway Service Providers (CGSPs) directly provide, subcontract or broker care and support services in the home and community, including personal care, domestic assistance, transport, nursing, respite and social support for care recipients, enabling carers to access breaks from the caring role both in planned and emergency situations and sustain their caring role.

In many cases, these services are delivered by organisations and workers who are also operating within the aged care and/or disability service systems. Both systems have their own distinct and comprehensive compliance and reporting requirements. Taking on additional compliance checks in order to operate within Carer Gateway can therefore be perceived as adding too much complexity, limiting the service options available to carers. A single assessment and audit process used across all direct care service systems would allow more service providers to operate within multiple systems – including Carer Gateway – providing more choice to service users and helping to address workforce shortages.

Centralised information about provider registration and approval across aged care and disability services would also allow CGSPs – as well as service users and their carers – to access and monitor

¹ Australian Bureau of Statistics (ABS) (2019a) *Disability, Ageing and Carers, Australia: Summary of findings, 2018*, New South Wales Tables, Canberra.

² www.carergateway.gov.au

safety and quality information more easily. The recent addition of the “Quality” and “Compliance” tabs on the My Aged Care provider finder web page are a good example of how this can be achieved. However, this information must be easy to find, interpret and understand for carers and the people that they care for, as carers have reported to Carers NSW that they did not know that the quality and compliance information was available on My Aged Care or how to interpret it.

An overarching, independent quality and safety body for complaints regarding concerns about all direct care services, similar to the NSW Health Care Complaints Commission (HCCC)³ which deals with all health care related complaints in NSW, would also enable complaints regarding services delivered under Carer Gateway to also be pursued, with redress actions against providers actioned across all service systems (Appendix B).

The benefits of regulatory alignment of the care and support sector

Sustaining informal caring arrangements by improving care quality and safety

Carers are often highly involved in the planning and organisation of aged care services with, or on behalf of, the person that they care for. The Carers NSW 2020 National Carer Survey⁴ found that, of respondents caring for someone receiving aged care services, 88.1% provided assistance with coordinating support services or care workers, 82.7% provide support with cognitive and emotional tasks such as decision making and 73% provide administrative support to the person that they care for. Additionally, the Survey⁵ found that, of respondents providing support to a person with disability, 85% helped the person coordinate support services, 80% provided support with cognitive and emotional tasks, and 70% were involved in advocating for the needs of the person they care for.

In spite of their central role, many carers report that they find it difficult to locate and understand information about quality and safety of aged care and disability services using current Government online platforms. The Carers NSW 2020 National Carer Survey⁶ found that 1 in 4 respondents caring for someone receiving aged care services, and 36.1% of respondents caring for someone receiving disability services, had difficulty finding information about services. While 2 in 3 respondents caring for someone receiving aged care services agreed that services met their expectations of quality and safety, only 1 in 2 respondents caring for someone receiving disability services agreed with this statement.

Recent analysis of findings from the Carers NSW 2020 National Carer Survey⁷ (Figure 1.) indicate that there is a strong, statistically significant connection between whether a carer's expectations of aged care quality and safety are met (measured with a 5-level Likert item), and both carer wellbeing (measured through the Personal Wellbeing Index) and psychological distress (measured through the Kessler 5-item Psychological Distress Scale). There was a large effect of perceived quality and safety of services on carer wellbeing, and a medium effect on psychological distress. It is expected that findings would be similar for carers providing care and support to people receiving disability services.

While many carers choose to take on a caring role, caring can have significant negative impacts on their health and wellbeing, social connectedness and finances, especially where they may be hesitant to engage with formal care services due to concerns about quality and safety. Additionally, many carers report to difficulty accessing information about service quality and safety that is independent, easy to find and easy to interpret, creating greater work and stress for carers, and limiting confidence in the quality and safety of services.

³ <https://www.hccc.nsw.gov.au/>

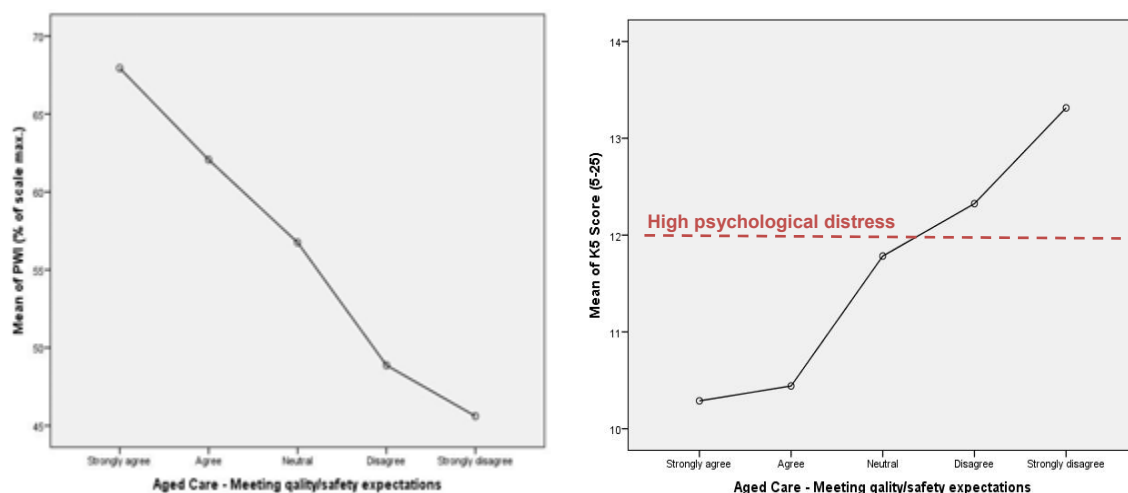
⁴ Carers NSW (2020) *2020 National Carer Survey*, unpublished data.

⁵ Ibid.

⁶ Ibid.

⁷ Ibid.

Figure 1. Connection between perceived quality and safety of services, wellbeing and psychological distress



Carers NSW commends the Department, the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission on their ongoing work to improve quality and safety information available on through their online platforms. However, Carers NSW believes that there must be clear measurement and reporting on care quality, with reporting publicly available, easily accessible and understandable, in a range of formats to support carers and the people that they care for when considering which service providers to access. This will help carers and consumers feel safe and confident engaging with services and reduce carer strain.

Improving service navigation and streamlining complaints pathways for carers accessing multiple service systems

As highlighted by the significant engagement of carers in the recent Royal Commissions into Aged Care Quality and Safety (Aged Care Royal Commission) and the ongoing Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), carers often play an important role in safeguarding the person they care for. They often assist the person they care for to identify appropriate, high quality services, monitor the ongoing quality and safety of these services, and identify and report quality and safety concerns. However, many carers report confusion about complaints mechanisms and, especially when they are engaging with multiple service systems.

"I need to constantly monitor the level of care my partner receives, request information, demand access to specialist services, etc in order to ensure he gets the quality care he deserves."

- 2020 National Carer Survey response

Sandwich carers

With the Australian population ageing, a preference for ageing in the community and long delays to access aged care services, people are increasingly acting as 'sandwich carers', caring for a child or children, as well as a family member who is ageing.

Providing care to a child or children (<15 years) with additional needs as well as an ageing family member can have significant impacts on a carer's health, wellbeing, social engagement and finances. While many carers experience negative outcomes of caring, impacts for sandwich carers are exacerbated. The Carers NSW 2020 National Carer Survey found that 95.2% of respondents caring for both a parent and child/ren with additional needs were women, and their mean age was 50.8.

The Survey found that sandwich carers reported lower wellbeing than other carers (a mean score of 50.8 on the Personal Wellbeing Index compared to 58.7 for other carers). Additionally, 56.4% of sandwich carers reported high/very high psychological distress on the Kessler Psychological Distress Scale-5, compared to only 46.3% of other carers. Sandwich carers were also found to be more socially isolated than other carers.

Despite reporting higher levels of engagement in the labour force than other carers, the Survey found that more sandwich carers reported financial stress in the prior 12 months, with near 1 in 5 reporting financial distress.

The 2018 SDAC found that 447,800 carers, or approximately 1 in 6, provide care or support to more than one person, which often involves engaging in more than one care service system.⁸ Additionally, the Carers NSW 2020 National Carer Survey⁹ found that a vast majority of respondents who were caring for someone receiving formal care services (aged care, disability [NDIS] care or mental health care) or receiving formal support themselves (Carer Gateway services) were engaged with two or more service systems (Figure 2).

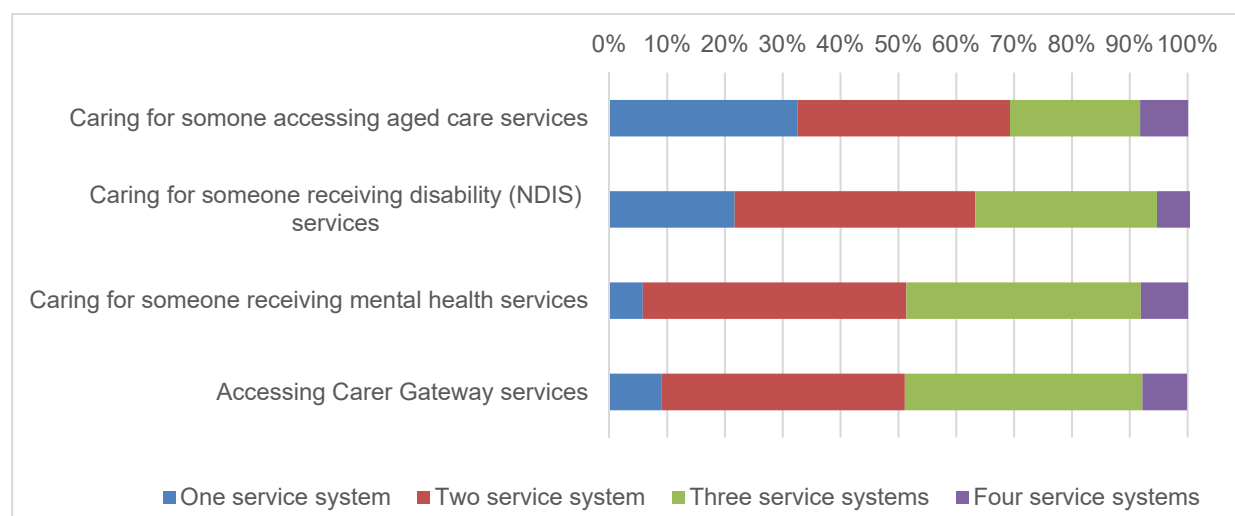
For example, the Survey¹⁰ found that only 1 in 3 carers accessing aged care services for the person they cared for were *only* engaged with that service system, with 2 in 3 also caring for someone accessing another service system, or accessing support for themselves through Carer Gateway. Similarly, only approximately 1 in 5 carers accessing disability services with or on behalf of the person they cared for were *only* engaged with the disability care sector, with more than 1 in 3 (37.4%) engaged with three or more service systems.

⁸ Australian Bureau of Statistics (ABS) (2019b) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset. Australian Government, Canberra.

⁹ Carers NSW (2020).

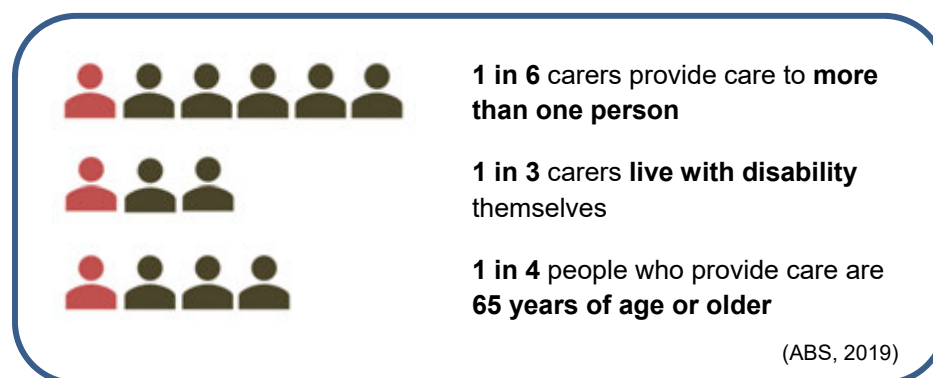
¹⁰ Ibid.

Figure 2. Number of service systems carer engaged with (including aged care services, disability [NDIS] services, mental health services and Carer Gateway services)



Many carers may also be accessing services and supports for themselves through different service systems than the people that they care for. The 2018 SDAC¹¹ indicated that approximately 1 in 3 carers live with disability themselves, much higher than the rate of reported disability for non-carers, and almost 1 in 4 carers (24.5%) are aged over 65 years. In regards to cross-sector caring relationships, whereby a carer and their care recipient are both likely to be accessing different service systems for support, the 2018 SDAC¹² indicated that 40.0% of primary carers (165,600 primary carers) who provide care to someone over 65 reported that they live with disability and 76.8% of all primary carers aged 65 years and over (183,300 primary carers) provided care to someone with a disability.

Figure 3. Prevalence of multiple caring roles, disability and ageing among carers



Additionally, carers may be engaged with a range of other service systems such as the health care system or mental health care system, all of which have their own quality and safety, complaints, and redress mechanisms as well. Carers NSW believes that it is vital to align regulation between sectors and streamline complaints pathways to minimise the administrative burden experienced by carers. This will better enable carers to act effectively and confidently as safeguards for the people they care for.

¹¹ ABS (2019b).

¹² Ibid.

Workforce growth and development

Many carers, especially those in rural and regional areas or other 'thin markets', have expressed challenges finding and maintaining services for the person they care for due to significant care workforce shortages. Carers NSW has also experienced challenges brokering services from disability and aged care providers in the delivery of Carer Gateway carer directed supports and emergency respite due to thin or fully exhausted markets in regional NSW.

As the Carer Gateway Service Provider (CGSP) in Hunter New England, Central Coast and North Coast NSW, Carers NSW has heard from our sub-contractors, as well as from a range of providers in the community, that administrative time and costs associated with undergoing quality and safety auditing across multiple sectors has prevented them from expanding their services to other care sectors, even when they may otherwise have capacity to do so.

Furthermore, ongoing changes to the nature of employment in care sectors, resulting in insecure and variable hours, have seen an increasing number of paid care workers finding employment across multiple care sectors (i.e. aged care, disability and health). However, paid care workers may be hesitant to work across sectors or may have difficulty accurately implementing quality and safety requirements or schemes, such as incident reporting schemes. Differing rules and procedures across care sectors cause confusion for paid care workers, potentially reduced compliance with quality and safety measures and placing vulnerable persons at greater risk of abuse or neglect.

Carers NSW has on a number of occasions raised concerns that a lack of consistency in the regulation of quality and safety across care and support sectors may undermine workforce growth, as well as the quality and safety of care. Carers NSW has also advocated for consistency in regulatory and compliance measures between the aged care, disability and health sectors wherever reasonably practicable, as this is likely to foster growth in the market and workforce, as well as see optimal compliance with all quality and safety measures.

Aligning regulatory measures in practice

Regulatory assurance of providers across the care and support sector

Given ongoing workforce shortages and the impact of this on access to services and supports for carers and the people that they care for, Carers NSW believes that all providers of direct care services to people with disability, people who are ageing, or veterans should be required to undergo one consistent, streamlined, cost efficient assessment to determine that they meet a core set of quality and safety standards that could be expected of all direct care providers. There should also be options to 'add-on' to the core quality and safety standards to ensure that providers are adequately skilled to provide care and support to specialised groups based on need (e.g. behaviour support, dementia care, palliative care, nursing care, residential care).

Currently within the NDIS this type of model already exists, with registered NDIS providers required to adhere to the NDIS Practice Standards, against which they can assess their performance and demonstrate high quality and safe supports to NDIS participants. Within the Practice Standards there are four core modules, there are also six supplementary modules that enable providers to be assessed in more complex or specialised areas. While Carers NSW does not necessarily feel that the NDIS model should be extended or used as a basis for the regulation of care provider quality and safety accreditation, a similar model may be effective in enabling one streamlined assessment of the quality and safety of care services.

One combined list of 'registered' or 'approved' care and support providers should be available and searchable to enable people requiring support and those that care for them to confirm that providers have met minimum standards. Current databases of registered providers such as that available

through the NDIS Quality and Safety Commission website¹³ and the Voluntary out-of-home care register,¹⁴ available through the NSW Office of the Children's Guardian provide good examples of these types of registers. The register should also make clear which additional modules service providers have been assessed against or approved to deliver, and be kept regularly updated to ensure currency.

Carers NSW understands that currently within the NDIS there are a number of unregistered providers, with many reporting that they are unable to meet high costs associated with auditing. Carers NSW believes that in order to ensure that all providers receive a minimal standard of independent, external oversight in regards to quality and safety, while maintaining maximum choice for care recipients and their carers, registration of all direct care providers must be mandatory. However, to enable this, auditing processes must be low- to no-cost and creating minimal administrative burden for providers. Ensuring that all providers are able to, and do undertake auditing and registration processes will likely see improved quality and safety of care while maintaining depth in the market.

Creating a streamlined, supportive complaints pathway for the care and support sector

Carers NSW believes that there should be one entry point for all complaints or concerns regarding the quality and safety of direct care and supports. This must also integrate with state and territory regulatory bodies such as the NSW Ageing and Disability Commissioner, enabling warm referrals, and reducing the need for carers to contact multiple agencies or re-tell their story.

There must also be adequate support available to carers seeking to make complaints with or on behalf of the person they care for, including advocacy support, as well as counselling where appropriate and necessary. Carers NSW has heard from many carers that they, or the person they care for, are hesitant to raise complaints with service providers directly or with the appropriate complaints body, as they fear this will negatively implicate the care recipient or jeopardise their service arrangements.

Carers have reported to Carers NSW that in some cases, where they have raised concerns about the quality and safety of services received from NDIS providers, the provider has made subsequent attempts to exclude them from service planning and delivery, in some instances applying for guardianship of the care recipient or challenging guardianship orders that may already be in place.

Carers NSW has concerns that where adequate protections are not in place for carers to raise complaints, they may be reluctant to do so. This is likely to place participants under greater risk of abuse, neglect and exploitation from service providers. There must therefore be mechanisms in place to ensure that carers and the people that they care for can access support when making complaints.

Improving quality and safety mechanisms through consistency and information sharing

Carers NSW has on many occasions addressed to the need to ensure consistency in regulatory measures and information sharing between sectors to maximise compliance and effectiveness. Consistency in Serious Incident Response Schemes, codes of conduct, standards of care, minimal qualifications for direct care workers and national worker screening mechanisms are necessary for ensuring quality and safety of care across the whole of the direct care and support sector.

Furthermore, Carers NSW has also previously raised concerns that consistency alone will not address ongoing issues in the regulation of quality and safety across care sectors and that information sharing between sectors is also key. For example, inadequate information sharing between care and support sectors has seen banning orders issued in one sector not precluding

¹³ <https://www.ndiscommission.gov.au/resources/ndis-provider-register/search>

¹⁴ <https://www.ocg.nsw.gov.au/voluntary-out-of-home-care/find-a-service-provider-near-you>

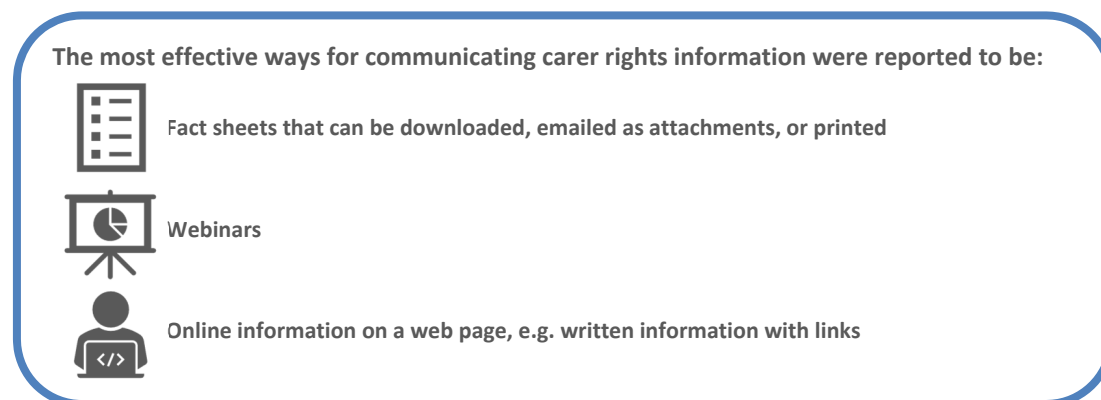
workers or providers from switching to another care sector (e.g. moving from disability services to aged care following compliance actions in the disability sector), placing vulnerable individuals and their carers at risk. There are concerns that failure to enable information sharing between sectors or alternatively, to move to one quality and safety body that operates across all sectors, is likely to undermine the effectiveness of alignment.

Providing quality and safety information in multiple formats

Carers NSW understands that, due to the need to ensure accessible information is kept up to date and searchable, quality and safety information about providers is provided through online platforms such as My Aged Care. However, Carers NSW has concerns that the ongoing move to digital information as the only option is likely to create further barriers for carers in understanding the level of quality and safety that they can expect, identifying appropriate providers, and accessing information about making complaints.

The 2018 SDAC found that 15% of primary carers in Australia, or approximately 120,000 primary carers in total, reported that they had not used the internet in the last 3 months.¹⁵ Of those primary carers, the most common reasons for not accessing the internet were that they have no need/no interest (74%), lack confidence/knowledge in accessing the internet (27%), can rely on friends/family to use the internet for them (13%) and no access to a computer or mobile technology (13%).¹⁶ Additionally, Carers NSW recently held a stakeholder workshop in partnership with NSW Department of Communities and Justice (DCJ), on behalf of the Carer Rights and Complaints Network (CRCN) in relation to Phase 2 of the Carer Rights Education project. The workshop found that carers prefer to receive information about carer rights and complaints pathways through factsheets that can be downloaded, emailed as attachments or available as a paper copy (Figure 4).

Figure 4. Findings from the Carers NSW Carer rights & complaints: Stakeholder workshop



As highlighted by Australian Human Rights Commission,¹⁷ carers are over-represented in groups with low rates of digital inclusion and as such may face significant barriers to accessing digital service systems. While many carers are highly digitally literate, the increasing digitalisation of services, increasing cost of digital devices and reduced access to public spaces that provide digital access (e.g. libraries) due to COVID-19 related social distancing measures, are likely to result in some carers being unable to access digital quality and safety information about service providers.

¹⁵ ABS (2019).

¹⁶ Ibid.

¹⁷ Australian Human Rights Commission (AHRC) (2019), *Human rights and technology: Discussion paper*, AHRC: Sydney.

Carers NSW believes that information about the quality and safety of services, including information about complaints and redress mechanisms, should be provided in a range of formats, including easy read and translated resources. In addition, there should be opportunities for people receiving care and support services and their carers to access over the phone or in-person support from quality and safety bodies or navigation supports (i.e. Care Finders, Local Area Coordinators) to enable them to access and fully understand quality and safety information. This is likely to see carers and their care recipients better equipped and able to engage with formal care services, reducing strain on informal carers.

Conclusion

Carers NSW again welcomes the initiative to align regulation across the care and support sector and thanks the Department for the opportunity to provide feedback on this matter. Carers NSW believes that aligning regulation is key to ensuring that the care and support sector is able to meet the increasing demand for care in the community and that services and supports are of high quality and safety and do not place care recipients or the people that they care for at risk. However, any alignment of regulation must take into consideration the nuances in experiences and needs of different groups requiring support and their carers, and ensure that regulatory measures can be adapted or specialised to enable high quality and safe care for all Australians.

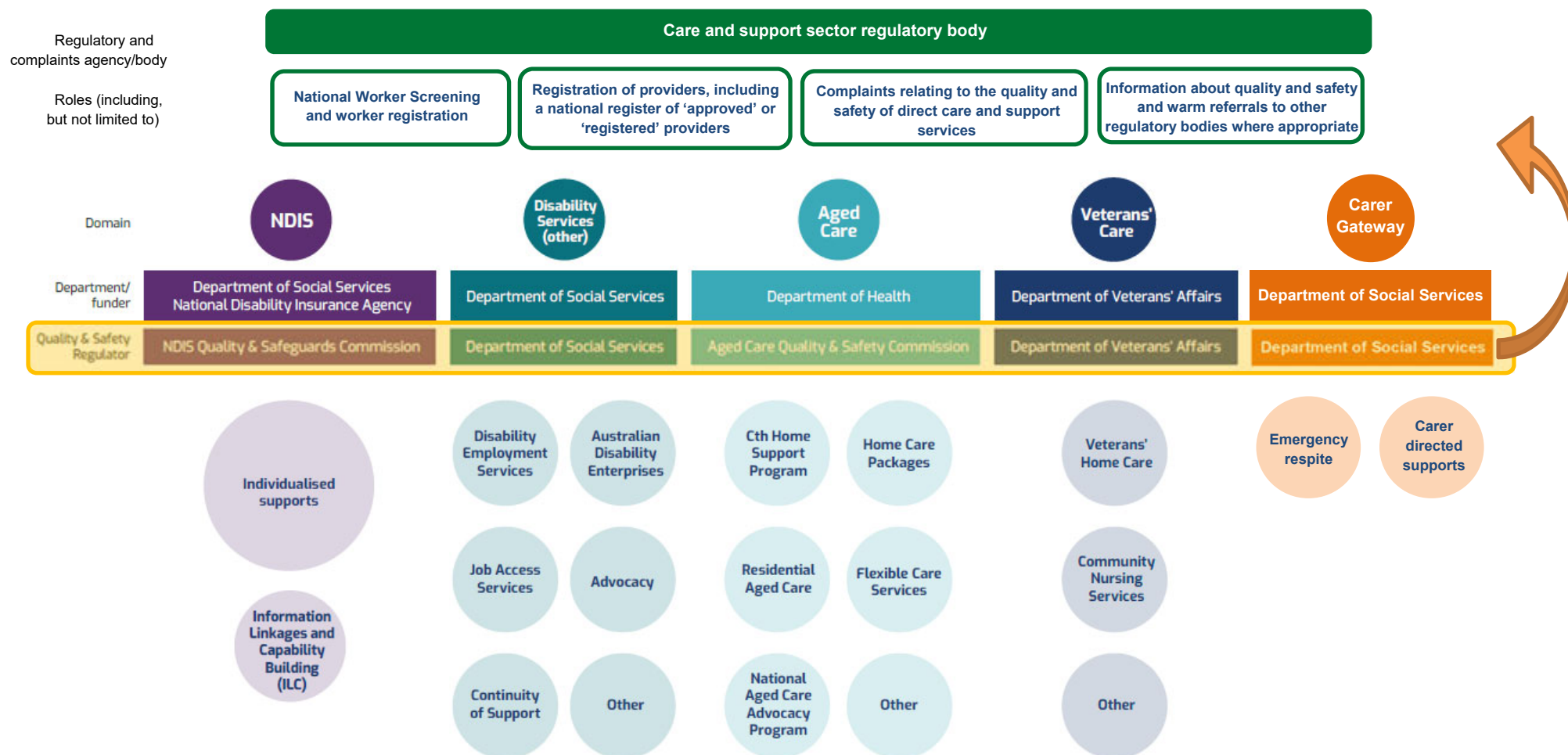
Appendix A

Table 1. Carers NSW previous submissions pertaining to aligning regulation across the care and support sector

Submission/Report	Accessible online at:	Area/s of focus
Carers NSW submission to the Royal Commission into Aged Care Quality and Safety in response to Workforce issues (2019)	https://agedcare.royalcommission.gov.au/system/files/submission/AWF.650.00065.0001.pdf	A consistent National Worker Screening program across care and support sectors
Carers NSW submission to the Joint Standing Committee on the NDIS inquiry into the NDIS workforce (2020)	https://www.aph.gov.au/DocumentStore.aspx?id=b9eace1a-3d6c-4844-b27a-7055ef6967b3&subId=680189	A single care workforce requiring consistency in quality and safety measures
Carers NSW workforce briefing for Department of Social Services in relation to workforce issues impacting on Carer Gateway service delivery	(Briefing not publicly available)	Recommendations - Better integrate and streamline the policy, regulation and funding of the aged care and disability workforces, since there is considerable overlap.
Carers NSW submission to the Department of Health on the Serious Incident Response Scheme in in-home aged care services (2021)	(Submissions not published online)	Consistency in Serious Incident Response Schemes between care and support sectors
Carers NSW submission to the Senate Standing Committees on Community Affairs in response to the <i>Aged Care and Other Legislation Amendment (Royal Commission Response No. 2) Bill 2021</i> (2021)	https://www.aph.gov.au/DocumentStore.aspx?id=4d2936c8-0638-48a5-8481-3f108de14c8e&subId=716875	- Consistency across sectors of a National Worker Screening program - Code of conduct and banning orders in aged care - Extension of incident management and reporting in aged care - Increased information sharing between quality and safety agencies
Carers NSW Pre-Budget Submission 2022-23: Caring through times of change	https://www.carersnsw.org.au/news/carers-nsw-pre-budget-submission-2022-23	Improving integration between state and federal safeguarding agencies and bodies

Appendix B

Figure 1. A vision for regulation of Australia's care and support sector



Appendix C

Table 2. Proportion of carers accessing multiple service systems based on service use overlap in Carers NSW 2020 National Carer Survey

Service system use	Frequency	Percent
<i>Service use overlapping with aged care</i>		
Only Aged Care	797	32.6%
Aged Care and Disability Care	195	8.0%
Aged Care and Mental Health (MH) Services	218	8.9%
Aged Care and Carer Gateway	484	19.8%
Aged Care, Disability Care and Carer Gateway	147	6.0%
Aged Care, Disability Care and MH Services	237	9.7%
Aged Care, MH Services and Carer Gateway	167	6.8%
Aged Care, Disability Care, MH Services, and Carer Gateway	202	8.3%
<i>Total</i>	2447	100%
<i>Service use overlapping with Disability Care</i>		
Only Disability Care	712	21.0%
Disability Care and Aged Care	195	5.7%
Disability Care and MH Services	737	21.7%
Disability Care and Carer Gateway	483	14.2%
Disability Care, Aged Care and Carer Gateway	147	4.3%
Disability Care, MH Services, and Carer Gateway	681	20.1%
Disability Care, Aged Care and MH Services	237	7.0%
Disability Care, Aged Care, MH Services, and Carer Gateway	202	6.0%
<i>Total</i>	3394	100%
<i>Service use overlapping with Carer Gateway Services</i>		
Only Carer Gateway (CG) Services	143	5.8%
CG Services and Aged Care	484	19.7%
CG Services and Disability Care	483	19.6%
CG Services, and MH Services	154	6.3%
CG Services, Aged Care, and Disability Care	147	6.0%
CG Services, Aged Care and MH Services	167	6.8%
CG Services, Disability Care, and MH Services	681	27.7%
CG Services, Aged Care, Disability Care, and MH Services	202	8.2%
<i>Total</i>	2461	100%
<i>Service use overlapping with Mental Health Services</i>		
Only Mental Health Services	242	9.2%
MH Services and Aged Care	218	8.3%
MH Services and Disability Care	737	27.9%
MH Services, and Carer Gateway	154	5.8%
MH Services, Aged Care, and Disability Care	237	9.0%
MH Services, Aged Care and Carer Gateway	167	6.3%
MH Services, Disability Care, and Carer Gateway	681	25.8%
MH Services, Aged Care, Disability Care, and Carer Gateway	202	7.7%
<i>Total</i>	2683	100%