

16 December 2022

Department of Communities and Justice Seniors Team
Locked Bag 5000
Parramatta NSW 2124

Carers NSW welcomes the opportunity to provide a submission to the Department of Communities and Justice (the Department) in response to the review of the NSW *Ageing and Disability Commissioner Act 2019* (the Act). Carers NSW commends the NSW Ageing and Disability Commission (ADC) and the NSW Ageing and Disability Commissioner (the Commissioner) on their supportive, carer-inclusive approach to preventing and responding to abuse and neglect in the community. Carers NSW believes that this review provides a welcome opportunity to build on the strengths of the approach and work of the ADC and Commissioner so far by expanding and strengthening their functions and increasing the carer-inclusiveness of their information and processes.

Additionally, Carers NSW would like to highlight the need for greater clarity in the legislation and other documentation regarding the distinctions between the ADC and Commissioner. In line with the current Act and discussion paper, this submission refers to the roles and functions of the Commissioner.

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 welcomes the opportunity to provide feedback to the NSW Department of Communities and Justice on the review of the *NSW Ageing and Disability Commissioner Act 2019* (the Act). Carers NSW would like to commend the work of the NSW Ageing and Disability Commissioner (the Commissioner) since their establishment. Since its establishment, Carers NSW has worked closely with the Commissioner through participation in the NSW Ageing and Disability Commission Board and the Ageing and Disability Roundtables, as well as through two one-off projects in 2022.

Carers NSW commends the carer-inclusive approach of the Commissioner and the supportive and educative approach taken in responding to reports of abuse or neglect which recognises the complexities and nuances of family and caring relationships. Carers NSW believes that the Act should continue to uphold the principle that ‘families, carers and other significant persons have a crucial role in the lives of adults with disability and older adults and it is important to respect and preserve those relationships’ in line with the *NSW Carers (Recognition) Act 2010*. Carers NSW also believes that there are a number of further opportunities to extend the scope and functions of the Commissioner, as well as continue to build on its carer-inclusive practice.

Expanding the scope and functions of the Commissioner

Expanding the scope of the Commission

Carers NSW recognises the important role of the Commissioner in addressing abuse and neglect towards people who are ageing and people living with disability, two particularly vulnerable groups in the community. However, Carers NSW believes that there should be consideration of the extension of the role of the Commissioner to prevent and respond to abuse towards persons with additional vulnerabilities more broadly.

In South Australia, the Adult Safeguarding Unit¹ can respond to concerns about any adults who may be vulnerable and experiencing abuse or mistreatment. This includes adults who may be vulnerable due to age or disability, however it also includes adults who may be vulnerable due to other factors such as ill health, social isolation, dependence on others, or other disadvantage. Carers NSW believes that in the review of the Act, consideration should be given to whether the scope of the Commissioner be extended more broadly to enable pathways for other vulnerable adults and their carers to access support or seek redress where abuse or neglect may be occurring. Within NSW there is no other such place that fulfils this role and Carers NSW feels that it would fit best within the scope of the Commissioner.

Additionally, while some carers do perpetrate abuse, carers can also be reporters of abuse or experience abuse themselves. Carers often report high levels of social isolation, high psychological distress, long term illness or disability themselves and financial disadvantage² which can make them particularly vulnerable to abuse or neglect in the community. Carers who experience abuse perpetrated by the person they

Michelle reported that police were recently dispatched to respond to an incident involving the person she cares for, who lives with intellectual disability. Michelle reported that the police who responded had not been properly trained to work with people with intellectual disability. The resulting experience was very distressing for Michelle and the person she cares for.*

*Names changed for privacy

¹ SA Health (not dated) *Adult Safeguarding Unit*, available online at: <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/department+for+health+and+wellbeing/office+for+ageing+well/adult+safeguarding+unit/adult+safeguarding+unit>, viewed 15 December 2022.

² Carers NSW (2022) *2022 National Carer Survey, Unpublished data*.

care for, often as a result of behaviours associated with their conditions, report to Carers NSW limited avenues for seeking support in these situations. In many cases, the only option available to carers to address these instances of abuse is through the justice system, however, this pathway is often not appropriate, may not be adequately equipped to respond to the complex and relational dynamics, and may reinforce systemic discrimination of people with disability within the justice system. Carers NSW believes that if the scope of the Commissioner is extended to include other vulnerable persons, this may create an avenue for carers to seek appropriate support where abuse against may have been perpetrated against them.

Resourcing and oversight of mediation services

Elder or family mediation provides a valued and effective pathway for resolving potential conflict within families and supports optimal outcomes for people who are ageing and their carers. Carers NSW commends the NSW Government on the continued funding of Relationships Australia NSW Let's Talk Elder Support and Mediation Service³. However, Carers NSW believes that this service should be available more widely and beyond the ageing context alone to include other caring situations, such as for people with disability, their families and carers. Furthermore, Carers NSW believes that there should also be avenues for carers to access mediation services in their own right.

Currently Carers NSW is not aware of any family mediation services that are available to people with disability and their families in the context of abuse prevention and safeguarding. However, the RANSW Let's Talk program has highlighted the effectiveness of this supportive, nuanced approach in resolving family conflict that may be contributing to or may result in the abuse or neglect of someone who is ageing.

Carers NSW believes that there should be consideration of the resourcing and oversight of mediation services within NSW to sit within the scope of the Commissioner to ensure that they are adequately available in the community. Additionally, Carers NSW believes that the Commissioner should be tasked with conducting a review of the availability and effectiveness of mediation services in NSW to determine and inform future funding for mediation services, including the expansion of mediation services where gaps currently exist. This would be similar in nature to the Commissioner's previous review of disability advocacy in NSW, which has informed the development of the NSW Disability Futures Advocacy Program.

Increased role as a provider as education and support

Carers are often portrayed as potential perpetrators of abuse against vulnerable persons in the community. While it is true that many instances of abuse and neglect involve family members, the recent Aged Care and Disability Royal Commissions have also highlighted the invaluable role of carers as observers and reporters of potential abuse and neglect. Additionally, some carers may be at risk of being victims of abuse themselves.

In some instances, inadequate formal or informal support in the community for carers or the people they care for can lead to carer stress or a breakdown in caring relationships, which can in turn increase the risk of harm to the carer or care recipient. However, little is known about the circumstances in which carer perpetrated abuse may occur, or how it could be prevented. Carers NSW is currently working with researchers from the University of NSW on a project commissioned by the Commissioner that aims to address this gap by analysing data regarding carers that are subjects of allegation in reports to the Commissioner. These findings are informing the co-development of resources for carers and service providers that are aimed at preventing abuse and neglect from occurring in the community.

³ Relationships Australia NSW (not dated) *Let's Talk: Elder Support and Mediation Service*, available online at: <https://www.relationshipsnsw.org.au/support-services/lets-talk-elder-support-and-mediation-service/>, viewed 04 November 2022.

So far, this project has identified a number of key risk factors associated with carers being subjects of allegation, and associated consultation with carers and key stakeholders has resulted in clear direction regarding how preventative messaging can be distributed among carers and service providers. Carers NSW recommends that the focus on communicating effectively with, and about, carers in the context of reported abuse and neglect continue, in consultation with carers themselves and the experts who work with them. Ongoing monitoring and improvement of the data regarding abuse and neglect, and carers' roles within these situations, will also be important additions to the national conversation about abuse prevention.

In line with these objectives, Carers NSW believes that there is an ongoing role of the Commissioner in relation to increased education and support for carers and the wider community that builds on the findings of current projects and aim to reduce abuse and neglect against vulnerable persons. This role should be enshrined within the Act to ensure adequate resourcing for the Commissioner to fulfil this function.

Implementation and oversight of a supported decision making framework in NSW

Many carers in NSW support the person that they care for to make decisions, however there are limited opportunities for carers to receive formal training or support with this. The Carers NSW 2022 National Carer Survey⁴ found that approximately 83% of NSW respondents provided support with decision making. Furthermore, 90.4% provided support with cognitive tasks, 76.6% with organising finances, 74.1% with handling finances and 82.8% with coordinating support services. Additionally, 73.6% provided support with communication, 16.7% with interpreting, 73% with advocacy and 91.5% with administrative tasks, all of which can play a key role in making, executing and communicating decisions.

Additionally, while carers often support the person they care for to plan for the future, these discussions can be sensitive, confronting and challenging to navigate. Many carers express concerns about making future care decisions on behalf of the person they care for where they may experience a reduction in decision making capacity, wanting to make the 'right' decision that would align with their will and preference.

The NSW *Carers (Recognition) Act 2010* highlights the role of carers as partners in care who often are experts on the person they care for, and who should therefore be recognised and included in decision making processes, where appropriate. However, in some cases carers will need the skills or tools to effectively participate in these processes. Carers NSW has recently been working closely with a number of experts in this area to identify opportunities to improve the understanding and implementation of supported decision making for carers, as well as professionals and the disability and aged care sectors more broadly.

Carers NSW believes that supported decision making should be considered as an alternative to the appointment of formal guardians, optimising the rights and choices of people with cognitive impairment and minimising the need for tribunals and litigation. However, in order to take a supported decision making approach, community members, including carers and professionals, need to be able to better assess the level and types of support needed with decision making and implement best practice support with decision making.

In line with the Australian Law Reform Commission's recommendation that state and territory legislation reflect National Decision-Making Principals,⁵ Carers NSW believes there may be a role for the Commissioner, as a supportive and rights-focused agency, in the development and implementation of a legislated supported decision making framework in NSW. This framework would aim to uphold the

⁴ Carers NSW (2022).

⁵ Australian Law Reform Commission (2014) Towards supported decision-making in Australia, available online at: [alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/1-executive-summary-2/towards-supported-decision-making-in-australia/](https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/1-executive-summary-2/towards-supported-decision-making-in-australia/), viewed 15 December 2022.

rights of people with disability and people who are ageing in regards to decision making. Additionally, education and training are key to building community capacity in supported decision making, and enabling optimal outcomes for carers and those they care for. As such, Carers NSW also believes that the Commissioner should have an ongoing role in the education and support of carers and the broader community to implement supported decision making within its functions. It should also be noted that adequate resourcing would be required to enable this to be effectively implemented.

Addressing emerging gaps in safeguarding

A number of sectors have recently, or are still currently undergoing reform of safeguarding bodies and mechanisms. This includes but is not limited to the safeguarding of children in NSW, as well as regulation of the quality and safety of aged care and disability services and supports. Carers NSW has concerns that gaps in safeguarding may have emerged as a result of these reforms and as such, there is a need to review the jurisdiction and functions of the Commissioner to ensure that any identified gaps are addressed within the role of the Commissioner where this would be appropriate. Additionally, where the Commissioner may have already taken on additional functions as a result of safeguarding reforms, there is a need to clearly outline these functions within the legislation to ensure clarity and accountability.

Following recent reforms to safeguards for children and young people in NSW, Carers NSW believes that there is a need in the review of the Act to ensure that no gaps have emerged in the safeguarding of children and young persons with disability. Where gaps may have emerged, especially in relation to children and young people with disability, Carers NSW further believes that there should be consideration of the role of the Commissioner in safeguarding these persons. Additionally, consideration should be given to whether current children's safeguarding arrangements and mechanisms are appropriate for or inclusive for children with disability, their families and carers and whether it may be more appropriate to extend the functions of the Commissioner to children or adolescents with disability in these instances.

Similarly, with ongoing reform in the aged care and disability service systems, it is important to ensure that the scope and role of the Commissioner aligns with changes to safeguarding arrangements and mechanisms to minimise duplication and gaps in safeguards. One such area in which this is of particular importance is in relation to the use of restrictive practices within the disability and aged care contexts.

Carers NSW understands that following changes to the regulation and oversight of restrictive practices under the National Disability Insurance Scheme (NDIS), that it was initially intended that the Commissioner play an important role in reporting on the use of restrictive practices for people accessing the NDIS in NSW. However, following initial consultation on the draft *Persons with Disability (Regulation of Restrictive Practices) Bill 2021*, it remains unclear as to whether the Commissioner holds any ongoing functions in relation to this. Carers NSW believes that any ongoing role of the Commissioner in relation to restrictive practices under the NDIS should be clearly defined within the Act to ensure clarity and accountability in relation to these functions.

Furthermore, the recent introduction of amendments to the Commonwealth *Aged Care Act 1997* and the *Quality of Care Principles 2014* aim to eliminate or minimise the use of inappropriate restrictive practices within residential aged care. These changes have seen the introduction of consent requirements for restrictive practices. Where consent cannot be provided by an individual, a restrictive practices substitute decision maker (RPSDM) can provide consent, however, this relies on existing legislation within states and territories regarding appointment of substitute decision makers for restrictive practices. While Carers NSW is still following up with the Department of Health and Aged Care (DOHAC) about the implications of this within NSW, Carers NSW believes that this implies that RPSDMs can only be appointed in NSW through formal guardianship arrangements as there are no other legislative mechanisms that enable the appointment of an informal substitute decision maker in relation to restrictive practices in NSW.

Carers NSW believes there may be scope for the Commissioner to play an important role in the appointment of RPSDMs where formal guardianship is not preferred by a person who is ageing or their carer, especially where inability to provide consent may be episodic. Additionally, Carers NSW believes that processes relating to the appointment of RPSDMs in lieu of formal guardianship arrangements should be outlined within the Act. This function would align with the intent and function of the Commissioner, promoting autonomy and choice through a preference for supported decision making wherever possible.

Strengthening existing functions of the Commissioner

Improving reporting against Australia's Disability Strategy

*Australia's Disability Strategy 2021-2031*⁶ outlines a plan to improve the lives of people with disability, this includes improving recognition and support for carers⁷. Carers NSW understands that under the current Act, the Commission has a role in reporting NSW progress against Australia's Disability Strategy (the Strategy). However, Carers NSW feels that this is not clearly defined within the Act. Carers NSW believes that the Act should be updated to reflect the new Strategy, replacing reference to the *National Disability Strategy*. Additionally, references to the expected frequency and depth of reporting against the Strategy should be added to enable greater clarity and accountability.

Strengthening the Official Community Visitor scheme

Carers NSW understands that the Commissioner currently has responsibility for coordinating the Official Community Visitor (OCV) scheme in relation to certain services providing accommodation to adults with disability and older adults. Some carers report to Carers NSW concerns about the quality and safety of services received by the person they care for within supported accommodation settings, this has been especially the case during COVID-19 where there has been restricted access to many supported accommodation settings. OCVs play an important role in supporting residents within these settings to have their rights upheld and to access supports that can help them where this may not be the case. These activities may enable carers to feel more confident that the person they care for is receiving high quality supports, or that they are aware of the appropriate pathways where they are not.

Carers NSW believes that this role could be strengthened by expanding the ability of OCVs to provide advice and information, especially information relating to concerns about the quality and safety of formal care with other relevant bodies such as the NDIS Quality and Safety Commission and Department of Communities and Justice. Furthermore, Carers NSW supports the proposal that disability service providers be required to notify the Commissioner of any new or changes to visitable services as there are limited alternative mechanisms for OCVs to be made aware of them.

⁶ Department of Social Services (2021) *Australia's Disability Strategy 2021 – 2031*, available online at: <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>.

⁷ *Outcome area 4: Personal and Community Support, Policy Priority 3: The role of informal support is acknowledged and supported.*

Increasing carer-inclusive processes and procedures

The role of consent in the investigation of reports

Carers NSW supports the autonomy of people who are ageing and people with disability, however Carers NSW has concerns that in some instances, the need for consent for the investigation of reports may be prohibitive in the identification and investigation of potential instances of abuse and neglect. Carers NSW understands that the Commissioner has been working with people to enable supported decision making with regards to consent. However, Carers NSW believes that the scope of investigations not requiring consent should be expanded to include situations in which the individual cannot be contacted, in line with the South Australian legislation as proposed in the discussion paper.

Additionally, Carers NSW also believes that where a person can be contacted but there are reasonable grounds to believe that consent has been withheld due to pressure or duress from the accused perpetrator, it should be within scope for the Commissioner to determine whether to proceed with the investigation.

Furthermore, Carers NSW has concerns about situations in which a person who is ageing or living with disability may be at risk of indirect abuse or neglect. For example, misuse of finances or refusal to initiate formal services by formal substitute decision makers that jeopardise the sustainability of informal caring arrangements, contribute to poor carer health and wellbeing and ultimately place the individual at heightened risk of further abuse or neglect in the community.

Carers NSW has heard from carers in two instances where they were unable to access formal support with providing care to an ageing family member due to another family member, who was acting as guardian or Enduring Power of Attorney, withholding funds or consent to initiate formal care services. In both instances, carers reported that this was having a significant impact on their health and wellbeing, and jeopardising the sustainability of caring arrangements. However, as they were continuing to provide care despite the challenges doing so, the older person was not experiencing abuse or neglect at that time and had limited insight into the significant impact of the situation on their carer. In one case, the person who was ageing was also unwilling to consent to intervention due to concerns about inciting family conflict, leaving the carer with no avenue to access support other than to enter into legalistic processes to challenge formal guardianship arrangements.

Patrick cares for his son Tom* who lives with intellectual disability. Patrick reported that he was concerned that his son Tom had abruptly moved out and was now living with his girlfriend Leila*. Patrick had previously obtained legal protections for himself and Tom from Leila due to abusive behaviour. However, Patrick had recently learnt that Tom had had these protective measures against Leila withdrawn and was now living with Leila and Leila's friend in what he believed to be an unsafe environment where Tom was being pressured to partake in illicit activities. Patrick acknowledged that Tom should be supported to make his own decisions and as such has never sought a formal guardianship arrangement, however Patrick expressed concerns about Tom's health and safety given the previous history of abuse perpetrated by Leila towards Tom and Patrick. Patrick reported that he did not feel that Tom would consent to an investigation by the Commissioner due to pressure from Leila and limited insight into the situation.*

* Names changed for privacy

Anita cares for her mother Sally* who is living with dementia. Sally lives with Anita who is her primary carer, however Sally's Enduring Power of Attorney is Anita's sister Pam*. Anita recently sought formal services through My Aged Care to support with Sally's care as her care needs have increased and Anita feels unable to continue caring without support. However, Pam has refused access to Sally's financial information and to Sally's funds to finance formal services as she believes this is an unnecessary use of Sally's funds. Anita reported increasing distress associated with her caring role, however she noted that Sally has limited insight into the amount of care Anita provides and the impact this is having on Anita and therefore does not see a need for intervention.*

* Names changed for privacy

Carers NSW understands that there are complex elements of these situations that may require input or action from NSW Trustee and Guardian or NSW Civil and Administrative Tribunal. However, Carers NSW believes there should be scope for the Commissioner to investigate cases without consent where abuse, such as financial abuse in the form of withholding of funds, may be indirectly creating an increased risk to their personal safety.

Informing carers and key care partners about reports and investigations

Under the current legislation, the Commissioner must share information with other organisations who need to know such as the Health Care Complaints Commission, Aged Care Quality and Safety Commission and NDIS Quality and Safeguards Commission. Carers NSW supports the ongoing mandatory reporting of referrals onto other appropriate regulatory bodies. Carers NSW respects the Commissioner's approach to autonomy and choice in the investigation of reports. However, within other service systems, regulatory mechanisms are clearly outlined, with minimum standards and requirements for paid healthcare and care providers, such as codes of conduct or quality standards. Breaches of these legislated quality measures by individuals can result in suspension or banning orders, ensuring that individuals or services cannot continue

providing services or supports that do not meet the prescribed level of quality and safety. Carers NSW believes that the Commissioner should be required to continue to report these instances when appropriate to support broader safeguarding across the community. Additionally, Carers NSW believes that there should also be an onus on the Commissioner to inform other important, involved parties where appropriate.

Carers NSW believes that where appropriate, information about reports and instances of abuse or neglect should be shared with service providers or key health professionals such as their GP as they can play an important role in the ongoing safeguarding of a person in the community, as well as in providing them information and support. Additionally, Carers NSW believes that there should also be capacity and a requirement of the Commissioner to inform carers of incidents of abuse or neglect where this may have implications in the provision of care.

Where abuse or neglect may occur, this can have a negative impact on a person with disability or someone who is ageing. The trauma associated with this abuse or neglect may result in increased psychological distress or exacerbation of existing conditions or associated behaviours. The NSW *Carers (Recognition) Act 2010* highlights that carers should be considered as partners in care, as such it is important that carers are made aware of instances of abuse or neglect to enable them to respond appropriately and adapt care provided appropriately in light of these potential changes or additional needs.

Furthermore, Carers NSW believes that if a service provider makes a complaint in regards to another family member or member of the community, it is important that a carer is made aware as the carer may play an important role in safeguarding the person they care for from the alleged perpetrator until a formal investigation is conducted. Carers are also uniquely placed to witness or identify abuse or neglect in the community, therefore engagement with, and inclusion of carers from the start of an investigation

into a report of abuse or neglect will likely enable access to additional key insights from carers on nuanced or complex situations or dynamics between family members or friends.

Conclusion

Carers NSW again thanks the Department for the opportunity to provide feedback on the NSW *Ageing and Disability Commissioner Act 2019*. Carers NSW believes that this review provides an opportunity to build on the strengths and effectiveness of the Commissioner's work to date, and to continue to support a carer-inclusive approach to reducing and preventing abuse and neglect in the community.