



**Carers Australia submission to the  
Royal Commission into Violence,  
Abuse, Neglect and Exploitation of  
People with Disability – Issues  
Papers *Violence and abuse of  
people with disability at home and  
Safeguards and quality***

**26 February 2021**

## ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Our vision is an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole.

We believe all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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## Introduction

This submission is made in response to the Issues Papers [Violence and abuse of people with disability at home](#) and [Safeguards and quality](#). This submission has been informed by the network of state and territory Carer organisations.

Carers Australia welcomes the opportunity to engage with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission). Carers Australia is committed to the rights of people with disability. Carers Australia wants to work with the Royal Commission, people with disability, disability representative organisations and advocates to reduce violence and abuse in the home, and to promote Australia's obligations under the *UN Convention on the Rights of Persons with Disabilities* to respect, protect and fulfil the human rights of people with disability.

Carers Australia is responding to both papers in this submission because there is overlap in the issues raised in each paper as they apply to carers and carer policy.

In this submission Carers Australia focusses on family and friend carers of people with disability; paid care workers and volunteers are not considered in this discussion. The distinction is important because loose references to carers who perpetrate abuse may conflate different groups of people who provide care, which can be misleading and also confuse or undermine policy responses.

It should also be noted that many carers themselves live with disability: over one-third of primary carers have a disability.<sup>1</sup>

## Discussion

### ***The role of carers in supporting informal and formal safeguards***

#### Informal safeguards

Carers can have a significant role in providing and supporting informal safeguards for people with disability. Carers often provide informal advocacy for and support self-advocacy by the people with disability they care for, alongside paid care workers, peak bodies and funded advocacy services. Carers can provide communication supports and informal advocacy for people with disability who require them, and can be part of a network of trusted individuals around a person with disability to provide informal oversight and

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<sup>1</sup> According to the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers 2018, over one-third (37.4%) of primary carers had disability, twice the rate of non-carers (15.3%). <<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#carers>> [accessed 22 February 2021]

support.<sup>2</sup> Carers are often a significant and integral part of a network of trusted relationships, and often come into contact with service providers and formal safeguards.

The Royal Commission might consider ways that informal carers could be supported to understand their role and build capacity as advocates as well as knowledge and capacity to uphold and promote the rights of people with disability. For example, opportunities for training or education in how to act as an informal safeguard and support self-advocacy in a way that enables people with disability to have choice and control in how they live, including taking risks.

### Formal safeguards

Carers of people with disability regularly come into contact with the disability, health, education and legal service systems that people with disability may use throughout their lives. For example, they may help to navigate complex systems such as the NDIS or Centrelink, attend health appointments or be present when support workers visit at home. They may be the ones to raise concerns about service quality or make complaints. As such, the Royal Commission could consider ways carers could be supported to learn about formal safeguards and the role they could play in supporting those formal safeguarding mechanisms.

For example, aspects of the developmental measures – particularly public awareness campaigns and cultural change programs to enhance knowledge of human rights and challenge discriminatory attitudes that may perpetuate and increase the risk of violence, abuse, neglect or exploitation – identified by the Royal Commission in its paper (p. 4) could be adapted for carers and work both to support informal and formal safeguarding and help to mitigate the risk of abuse by carers.

Indeed, educative and developmental measures aimed at carers – but perhaps also other members of a family or trusted network – could be one of the best ways to safeguard people with disability who may be at risk of violence, abuse, neglect and exploitation both when they use services and in other areas of their lives. In the case of young children and young adults with disability, parents and carers can also promote these approaches among other parts of their network as well as supporting them to help build skills, independence and confidence in their children and help to enable self-advocacy as they get older.

The Royal Commission might consider ways carers could be supported to increase their skills and knowledge about risk factors for abuse, violence and

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<sup>2</sup> According to the ABS Survey of Disability, Ageing and Carers 2018, the majority of primary carers (79.1%) resided in the same household as the person for whom they provided the most care.

exploitation, how to look for and identify potential abuse, and when and how to report it or otherwise take action.

## ***Violence and abuse of people with disability at home***

### General comments

Carers Australia recognises that people living with disability are more likely to feel unsafe in their home than people without disability, and that people with disability are almost twice as likely to experience violence and abuse as people without disability.<sup>3</sup> Carers Australia recognises the right of all people with disability to protection from all forms of violence and abuse – including gender-based aspects – within and outside the home.

Carers generally take on substantial caring responsibilities out of love and concern for the people they care for, often at a cost to their own financial future and health and wellbeing.<sup>4</sup> Such motivations do not lend themselves to perpetrating abuse, but it is the case that some carers may be violent and abusive within a care relationship. Abuse or neglect by a carer may not necessarily be an intentional, malicious or deliberate act. Not all carers will possess the necessary skills, capacity or knowledge to address the needs of the person being care for, or the resources to access education, support and training in support of their caring role.

Carers Australia acknowledges that sometimes abuse is perpetrated by family members and carers. Below Carers Australia has responded to the Royal Commission's request for information about potential risk factors, as they apply to caring relationships. Carers can experience a range of stressors: both related and not related to their caring role. Primary carers in particular can face a range of stressors – such as poor mental and physical health and financial stress – in addition to an often intense and demanding role. Carers Australia is in no way suggesting that such circumstances or stressors excuse or justify abuse, violence, neglect or exploitation of people with disability. They are, however, important to understand in order to formulate appropriate and holistic policy responses: for assessing a person's exposure to risk of abuse, identifying instances of abuse and to prevent that abuse in the first place.

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<sup>3</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Violence and abuse of people with disability at home*, p. 3.

<sup>4</sup> According to the ABS Survey of Disability, Ageing and Carers 2018, the three most common reasons primary carers gave for taking on a caring role were: a sense of family responsibility (70.1%), emotional obligation (46.6%), and ability to provide better care than anybody else (46.4%).

## Potential risk factors for abuse in a caring situation

Carers, particularly primary carers (i.e. those who provide the majority of informal assistance with core activities of daily living), can experience a range of stressors, such as financial stress and social isolation. Such stressors may in some circumstances be risk factors that contribute to or increase the risk of abuse.

A carer at risk of committing abuse is most likely to be experiencing a high level of emotional, financial, physical and psychological distress as a result of their caring role. According to the 2018 Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC)<sup>5</sup>, carers had the following characteristics:

- One third of primary carers spent on average 40 hours or more caring every week.
- Primary carers are more likely to live in households with lower equivalised gross household income: half (50.2%) of primary carers resided in a household with equivalised gross household income in the lowest two quintiles, twice that of non-carers (25.6%).
- The median gross personal income per week of *all* carers was \$800 per week, compared with \$997 per week for non-carers.
- In 2018, among carers of working age (15-64 years), primary carers were less likely to be in the labour force (58.8%) than other carers (76.6%) and non-carers (81.5%)
- Of primary carers of working age, 55.5% were employed; however, employment status varied with the hours of care per week that a primary carer was providing:
  - less than one-third (28.6%) of primary carers providing more than 40 hours of care a week to their main recipient were employed
  - in comparison, over half (52.8%) of those caring for the main recipient for less than 20 hours of week were employed.
- Primary carers were more than twice as likely to receive a government pension or allowance (38.4%) than other carers (17.2%) and non-carers (9.2%), with a government pension or allowance the main source of income for nearly a quarter (24.1%) of carers generally.

Data from the Carers NSW 2020 National Carer Survey<sup>6</sup> shows that of respondents:

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<sup>5</sup> See ABS 2018 Australian Bureau of Statistics Survey of Disability, Ageing and Carers.

<sup>6</sup> See Carers NSW website, 'Carers NSW 2020 National Carer Survey'

< <http://www.carersnsw.org.au/research/survey> > [accessed 23 February 2021]

- One in four carers receiving the Carer Payment were experiencing financial distress<sup>7</sup>
- Nearly half of the carers who responded reported high or very high psychological distress<sup>8</sup>
- One third of respondents felt highly socially isolated<sup>9</sup>.

These figures demonstrate the breadth of potential stressors related to their caring role that carers, particularly primary carers, may experience, and which may contribute to the risk of abuse.

Some research on elder abuse suggests that other factors not intrinsic to the caring relationship may contribute to the risk of abuse by carers.<sup>10</sup> First, personal attributes or individual circumstances of the carer, such as exhibition of aggressive tendencies prior to taking on the caring role, mental health issues, or drug and alcohol use. Second, familial circumstances, where abuse may be part of a historical or current family pattern of behavior. These personal and familial factors are also recognised as potential risk factors for abuse, violence and exploitation of people with disability.<sup>11</sup>

There are of course also broader social and cultural factors which place people with disability at higher risk of abuse and violence, including “stigma, discrimination, and ignorance about disability, as well as a lack of social support for those who care for them”<sup>12</sup>. While carers of people with disability will in many cases be more knowledgeable and less likely to stigmatise and discriminate against people with disability – particularly the people they care for – education, literacy and broader community attitudes may influence carer attitudes, decisions and practical approaches to care and lifestyle. It is true that people can hold conscious and unconscious prejudice and stereotypes of other people in different ways and for some people attitudes or prejudices about disability won’t automatically change because they have a child with disability. Early intervention to support carers and families will be needed in

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<sup>7</sup> Carers NSW, *2020 National Carer Survey: Summary Report*, p. 39. A household is considered to be in financial distress if it experiences four or more defined indicators of financial stress within a 12 month period (p. 41).

<sup>8</sup> Ibid, p. 35.

<sup>9</sup> Ibid, p. 35.

<sup>10</sup> See Carers Australia’s *Submission to the Australian Law Reform Commission: Elder Abuse and Commonwealth Laws*, August 2016 <<https://www.carersaustralia.com.au/submissions-reports/submissions/page/4/>>. See also Brandl, B & Raymond, J. A 2012, ‘Policy Implications of Recognising that Caregiver Stress is Not the Primary Cause of Elder Abuse’, *Generations: Journal of the American Society on Aging*, vol 36 no. 3, pp. 32-39 and World Health Organization 2006 ‘Elder Abuse and Alcohol fact sheet’.

<sup>11</sup> Queensland Government Department of Communities, Disability Services and Seniors, ‘Risk Factors’ < <https://www.communities.qld.gov.au/disability-connect-queensland/preventing-responding-abuse-neglect-exploitation/identifying-abuse-neglect-exploitation/risk-factors>>

<sup>12</sup> World Health Organization, ‘Violence against adults and children with disabilities’ <<https://www.who.int/disabilities/violence/en/>> [accessed 22 February 2021].

some cases; for example, to learn about their child's disability, to challenge their own ideas, and to meet other people living with disability to understand their individual experiences, but also be exposed to different communities and cultures (e.g. Deaf culture).

Carers Australia suggests that further research needs to be conducted on risk factors for abuse of people with disability perpetrated specifically by carers and family members in Australia. It should also be noted that carers can be at risk of being abused by the person they care for: this is an under-researched area which also deserves attention.

#### Different types of abuse may need different policy responses

As the Royal Commission notes in its paper (p. 2), domestic abuse in the home is not limited to deliberate acts of violence: it can include neglect, emotional and psychological abuse, financial abuse, exploitation and use of restraints. It is important the Royal Commission consider where different types of abuse warrant different responses and different preventative approaches. For example, some instances of neglect might be the result of ignorance of physical care needs. Similarly, some instances of financial abuse might be the result of ignorance of the legal obligations and rules around managing another person's finances.

#### Prevention, intervention and support

The following actions and approaches may help mitigate the risk of abuse by carers:

- Improved access to information and education for carers about what constitutes abuse, neglect and exploitation;
- Access to information and education about disability theories and models, and human rights approaches, translated into easily accessible formats with practical examples, scenarios and suggestions for carers. For example,
  - Scenarios that illustrate for carers what it looks like to care in a way that enables decision-making, dignity of exercising choice (including the right to make poor choices) and taking risks, as noted by the Royal Commission<sup>13</sup>.
  - Tailored resources for carers and parents of young children and young people with disability to support and enable development of empower self-advocacy and promote building individuals' skills, independence and confidence.

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<sup>13</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Safeguards and quality*, p. 3.

- Increase carers' awareness of availability of disability advocacy services, and when it may be appropriate to have an independent advocate available.

There are many excellent resources available on Disability Advocacy Resource Unit (DARU) website, like the excellent "How we talk about disability matters!: Understanding models of disability"<sup>14</sup> that could be used as a model for developing resources for carers. One avenue to deliver and promote these resources is through the Carer Gateway. (Better integration of referrals to the Carer Gateway into NDIS contact points – e.g. at the point of assessment or at planning meetings – would further support this.) For example, the Carer Gateway could include unaccredited online training that supports skills development e.g. about social and human rights models of disability, and what these mean in practical terms e.g. being involved in informal or formal supported decision-making arrangements.

#### Recognition and support for carers in their own right

In addition to these specific measures aimed at the prevention of abuse of people with disability, it is important the Royal Commission consider in its broader inquiry and policy responses – particularly in relation to any reform of the NDIS and disability sector – the specific needs of carers in their own right. Recent policy reforms to social service systems – principally aged care and disability sectors – have focused on the individual 'choice and control' of care recipients, supported by individualised funding. While this is an important shift with many positive aspects, the corollary impact on carers' ability to choose and have control over their own lives has remained largely unconsidered.

The *Carer Recognition Act 2010* aims to increase recognition and awareness of carers and acknowledge the valuable social and economic contribution they make to society. The *Statement for Australia's Carers* under the Act states that all carers should have the same rights, choices and opportunities as other Australians, and that carers should be acknowledged as individuals with their own needs within and beyond the caring role.

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<sup>14</sup> See DARU website <<http://www.daru.org.au/how-we-talk-about-disability-matters>> [accessed 13 January 2021].