

Recognising carers in the Victorian disability system

Carers Victoria submission to Review the Disability Act 2006

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About Carers Victoria

Carers Victoria is a not-for-profit organisation that helps families and friends in our community who are caring for someone who needs support due to ageing, disability, mental illness, or other significant health issues.

We are the state-wide peak body for all unpaid family and friend carers.

It is estimated that there are more than 700,000 unpaid carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition. People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend.

Our vision is to work for an Australia that values and supports all carers, and we want to ensure that caring is a shared responsibility of family, community and government.

We work to ensure that caring is a shared responsibility of family, community and government. We want to support carers better; we want to make carers' lives better. (this is the new text from the latest strat plan whereas the other text is from quite an old submission).



Executive Summary

Carers Victoria welcomes the opportunity to comment on the Review of the Disability Act 2006.

We note this is the Government's first opportunity to substantially revise the Act since the United Nations Convention on Rights of Persons with Disability (UNCRPD) was ratified by Australia in 2008 (the Optional Protocol being adopted in 2009).

We also note that it has been a time of significant time across the disability sector, and that Victorian Government's role in areas such as direct service provision has changed. We do however see the Victorian Government as maintaining a pivotal role in leading, facilitating and supporting a future system that can deliver real improvements for all Victorians living with disabilities and their carers.

Within this environment, Carers Victoria is keen to ensure that reform agendas recognise that many of our shared aspirations around promoting equality and inclusion are unlikely to be achieved by the State without unpaid carers of people with disability – family and friends who support their loved ones in all domains of life.

There are currently around 300,000 Victorians who are unpaid carers of people living with disabilities. As the peak body representing unpaid carers, Carers Victoria has drawn upon what carers have told us and other evidence to describe some of the key challenges for which legislative reform may deliver positive benefits.

This submission provides a summary of these and makes a series of five key recommendations for legislative change:

1. That the central role of carers in supporting Victorians with disabilities be recognised in disability legislation.
2. That the Objectives and Principles of the Disability Act include a commitment to proactive, flexible planning and support of both Victorians with disabilities and their carers across their life courses.
3. That a commitment to keeping families of children with disability together wherever possible be incorporated into disability legislation.
4. That new legislation require disability plans adopted by the Victorian Government, government departments and local governments to proactively acknowledge the role of carers and establish goals and priorities for those carers.
5. That disability legislation create a direct connection to the new Supportive Guardian or Administrator mechanisms enshrined in the Guardianship and Administration Act (2019).

Carers Victoria looks forward to working with carers, the Victorian Government and other partners to achieve a positive future for all Victorians living with disabilities and their carers that protects their rights, supports a systems based approach and makes it easier for them to fully participate in our community.

The role of carers in supporting Victorians with disabilities

INTRODUCTION

Carers Victoria welcomes the opportunity to make this submission to the Review of the Disability Act 2006.

We recognise that the disability 'landscape' has gone through significant changes over recent years with the introduction of the National Disability Insurance Scheme, changes to quality and safeguarding frameworks and an increasing and welcome emphasis on recognising and empowering Victorians living with disability.

What has, however, remained constant is the central role of unpaid carers in supporting Victorians living with disability. This review offers an outstanding opportunity to recognise that role and better integrate it into the future Victorian disability ecosystem.

Just like Victorians with disabilities, this group of carers are diverse, but they report common issues.

In reviewing the Disability Act and setting the new frame for Victoria into the future there is a unique opportunity to address some of these and build a future in which carers are better enabled to support Victorians living with disability to live their best lives.

This submission draws upon current evidence, the experiences and knowledge of Carers Victoria and most importantly, the views of carers.

WHO IS CARING FOR VICTORIANS WITH DISABILITY?

Currently, it is estimated that some 300,000 Victorians are unpaid carers of people with disability.¹ The replacement value of unpaid care is estimated to be some \$20 billion annually.²

The majority of carers of people with disability are partners but parents, children, other relatives, friends or neighbours also make significant contributions to the informal caring eco-system³. A large concentration of carers live in Victoria's cities with around 25% living in regional areas and 5% in rural areas.

The kinds of supports carers provide vary substantially and will change over time however they typically involve a combination of one or more of physical, social, and/or emotional support*.

Carers commonly assist their loved one with healthcare, self-care and transport.⁴ For individuals with profound or severe core activity limitations, over 90% of people with profound or severe core activity limitations receive assistance from carers with mobility being the most common type of assistance required.⁵

* For example, in the 2020 National Carer Survey carers reported they supported the person they care for with transport (79%), administrative support 78%, household chores (77%) and cognitive or emotional tasks (77%).

THE CHALLENGES EXPERIENCED BY CARERS

It is well recognised that Australians living with disabilities may experience poorer outcomes in many domains of life including health, education and employment.

Alongside this, there is extensive evidence to show similar impacts for the individual's carer(s) and family.

When unsupported and under-resourced, care responsibilities can negatively impact on the emotional and physical wellbeing of carers. Evidence shows that currently carers experience greater exhaustion, stress, anxiety depression, injury and physical ill health than non-carers. Unfortunately, this is the current experience of many Victorian carers⁶ which have flow-on effects for the people they care for.

Under current arrangements, many carers have fewer opportunities to experience social and recreational activities⁷ and have reduced capacity to participate in the Victorian economy.

Over 20 % of carers have exited the workforce to provide care or reduced their working hours, and this has longer and adverse impacts on their financial security in later life. These challenges are reflected in data collected via the Survey of Disability, Ageing and Carers (SDAC) which has consistently captured lower rates of employment among carers.

A range of barriers have been identified to carers successfully balancing their caring role with employment. For example, in recent research, nearly half of the Victorian respondents indicated they could not find employment that would allow them respond to an emergency or allow them to sufficiently check-in with the person they care for.⁸

Building recognition and support for carers – opportunities for legislative reform

Carers Victoria sees the current Disability Act review process as an opportunity to create the architecture for a future focussed system in which the rights of Victorians living with disability are upheld, their opportunities to fully participate in our community are maximised, and integrated approaches both encourage ‘joined up’ approaches to supporting these Victorians and their key supporters, including unpaid carers. A focus on the rights of both will be essential.

While the Victorian Government’s role in relation to direct service provision has been changing, it retains a key role in facilitating connections and promoting integrated approaches to the planning and delivery of services, supports and infrastructure that have the potential to enhance the quality of life of Victorians living with, or affected by, disabilities.

Carers Victoria recognises that legislative reform is but one element of a broader system of changes that will be needed to achieve our shared aspirations for Victorians living with disability and the people who care for them.

We have identified five key areas where legislative reform could make an important contribution to the future system by enhancing the recognition of the role of carers of Victorians with disability and ensuring this is reflected in a more integrated approach to key planning, support and service approaches:

1. Recognise the central role of carers in supporting Victorians with disabilities in legislation.
2. Adopt a life course approach to planning for and meeting the needs of Victorians with disabilities and their carers.
3. Commit to keeping the families of children with disability together.
4. Integrate planning for carers into disability planning at both state and local government level.
5. Strengthen the linkage to mechanisms for supportive guardianship and administration.

Not only will such actions help strengthen outcomes for both Victorians living with disabilities and their carers, but they will also contribute to real progress in various priority areas of the Victorian Government’s Victorian Carer Strategy 2018-22, including:

- › **Priority 1:** Carers have better health and wellbeing
- › **Priority 3:** Carers can access support and services that meet their needs
- › **Priority 4:** Carers have less financial stress
- › **Priority 5:** Carers are recognised, acknowledged and respect

RECOGNITION OF THE ESSENTIAL ROLE OF CARERS

Currently, the role of carers in supporting people with disability is often hidden or not well understood.

While Carers Victoria recognises the significant progress that has been made in empowering individuals with disability, there is the risk that the fundamental role that carers and other supporters may be overlooked, making it harder for them to effectively fulfil their role.

Carers report experiences of being excluded or disrespected in a range of settings including healthcare and education, despite them often playing a key enabling role in both. Active involvement of carers in planning, assessment and other activities can significantly enhance the outcomes of those processes by providing a richer set of insights.

Fortunately, we are beginning to see Victoria lead the way in changing this. For example, the Royal Commission into Victoria's Mental Health System recognised families, carers and supporters as making a substantial contribution to the wellbeing of the people they care for or support.

Commission recommendations that the value of carers be recognised in the proposed Mental Health and Wellbeing Act and that their value be recognised across the mental health system⁹, signal a seismic shift in the way carers are viewed and supported by the Government, clinicians and service providers.

Carers Victoria recommends that the future disability legislation adopt an approach consistent with the proposed Mental Health and Wellbeing Act and include in its objectives and principles a statement on the value of families, carers and supporters. This will provide consistency across sectors and ensure citizens with disability and their carers are equally recognised and their needs—together and individually- are supported.

RECOMMENDATION 1

That the central role of carers in supporting Victorians with disabilities be recognised in disability legislation.

A LIFE COURSE APPROACH TO MEETING THE CHANGING NEEDS OF PEOPLE WITH DISABILITIES AND THEIR CARERS

The needs of Victorians living with disabilities, and those of those carers, both change across their respective life courses.

For example, the needs of carers who are parenting a young child with disability differs significantly to what both the carer and the person with the disability will need when they are older. Challenges such as the changing health status of carers can have a significant impact on Victorians living with disabilities.

While this may be widely recognised and could be proactively planned for and managed, the current environment does not actually do so and the result can be problematic for all involved when there are significant changes.

Creating a future system that recognises the importance of considering needs across the life course for both the individual and their carers has the potential to reduce the number and/or impacts of changing circumstances. A more proactive, 'early intervention' approach has the potential to deliver significant benefits across the life course but requires a shift in culture and practise to achieve this systemic change.

Such an approach could, for example, help deliver real benefits to families where adult children with disability live with their ageing parents. The majority of Victoria's ageing parent carers are aged over 65 years¹⁰ and they commonly experience poorer health outcomes including higher rates of depression, divorce, poor physical health and functional impairments compared to their peers.¹¹

Without appropriate supports to facilitate long term succession planning and implementation, the person living with disability is often faced with crisis intervention when their parent becomes too unwell to continue their caring

role or dies. Such series of events can result in 'double shock' experience of grief for the person they share a care relationship with and loss of the family home and inappropriate accommodation arrangements as a result of rapid allocation during crisis.^{12,13}

The current review of disability legislation offers a unique opportunity to signal a shift from crisis support to proactive, planned support. Carers Victoria recommends that new legislation acknowledge the changing needs of Victorians with disabilities, and the people who care for them, across the life course and commit to reflecting these in planning, support and service approaches.

RECOMMENDATION 2

That the Objectives and Principles of the Disability Act include a commitment to proactive, flexible planning and support of both Victorians with disabilities and their carers across their life courses.

SUPPORTING FAMILIES OF CHILDREN WITH DISABILITIES TO REMAIN TOGETHER

It is well recognised that parenting a child with disability is more complex than parenting typically developing children. Parents must navigate complex health and service systems and barriers to inclusion in a variety of settings for their children and themselves.

They may experience many challenges, including (but by no means limited to) school transitions, adult mental health challenges, marriage breakdown or death. These, along with inability to access support, respite and other supports¹⁴, are some of the factors that can increase the risk of families being forced to 'relinquish' their child with disability to out of home care.

Creating a system that commits to minimising the risk of such relinquishment occurring would significantly benefit all involved – children, families, their communities and broader government. Importantly, it would prevent violation of the human rights of affected children, parents and other family members.¹⁵ We note that the Disability Royal Commission has touched upon this area and see this as strengthening the case for proactive commitment in this area.

Carers Victoria recommends that there be a positive commitment made through legislation to keeping families of children with disability together wherever possible, potentially through its inclusion as a principle.

RECOMMENDATION 3

That a commitment to keeping families of children with disability together wherever possible be incorporated into disability legislation.

INTEGRATE THE NEEDS OF CARERS INTO DISABILITY PLANNING

The current Disability Act mandates the Victorian Government implement State Disability Plans - a whole-of-Government approach to promoting and supporting the inclusion of people with disability.

Each government department as well as each local government is also expected to develop their own Disability Action Plan. State Disability Plan are increasingly outcome-focused, reviewed every three to four years and are open to public consultation and comment.

Unfortunately, the current framework established through the Disability Act 2006 does not adequately recognise the role and needs of carers of Victorians with disability, and this is reflected in limitations of current disability plans, which:

- › Create an artificial distinction between people with disability and carers; and
- › Often group service providers and unpaid carers together/treat them as interchangeable and substitutable when this is not the case.

The review of disability legislation offers an opportunity not just to formalise a role for carers, but to ensure that this critical relationship is recognised in disability plans.

Carers Victoria believes that establishing a requirement for such plans to actively recognise and consider the needs of both the individual and their carer will help ensure that those who rely on carers to help them address barriers to participation and equality are not left behind and give practical acknowledgement to the lived reality that the needs of and outcomes for people with a disability are often inextricably linked to that of their carers.

RECOMMENDATION 4

That disability legislation require disability plans adopted by the Victorian Government, government departments and local governments to proactively acknowledge the role of carers and establish goals and priorities for those carers.

STRENGTHENING CONNECTIONS TO GUARDIANSHIP AND ADMINISTRATION LEGISLATION

Carers often report they encounter challenges with service providers, health authorities and government agencies when these agencies expect the disabled adult to express their will and preferences verbally or in other ways. However, some disabilities severely limit a person's ability to do so.

As the person's natural support carers can be denied opportunities to assist and inform. For those with a strong individual rights focus, carers can be viewed as oppressive or overprotective.¹⁶ This can leave all people in such care relationships in legal limbo, unable to declare their intentions to vote, genuinely consent to medical treatment or create a bank account. These bureaucratic barriers also have an impact on carers who must navigate complex government services and systems without proper legal recognition.

Victoria's Guardianship and Administration Act (2019) is the first attempt by an Australian jurisdiction to legislate supported decision-making and recognise supportive guardians and administrators.

Many carers reported the systems related to previous guardianship and administration laws were complex to navigate. Victoria's Public Advocate notes many carers do not always understand the nature of these orders and may be overwhelmed by the reporting required for Appointees.¹⁷ Legislative recognition of supportive guardians and administrators is relatively new in Australia and globally; we understand there is likely to be a "build and learn" approach for some time. An essential component of this approach is highly skilled advocates who can support people with disability and their carers as individuals and partners in the care relationship.

Carers Victoria believes that new disability legislation offers an opportunity to proactively make the connection to the new scheme in light of the significant benefits that could flow to Victorians with disabilities and their carers by improving the lives of all people in care relationships in their efforts to comply with expectations about competence and the expression of will and preferences by service providers, health authorities and government agencies.

This will support long-term data collection and evaluation necessary to understand whether the intention of the legislation to achieve greater inclusion of people with disability in society, is being realised.

RECOMMENDATION 5

That disability legislation create a direct connection to the new Supportive Guardian or Administrator mechanisms enshrined in the Guardianship and Administration Act (2019).

References

1. Australian Bureau of Statistics (2020) Survey of Disability, Ageing and Carers; Table 34.1 .
2. This figure is calculated as a proportion of the 2.6 million Australian carers estimated by the ABS. The cost of replacing informal care in Australia is estimated to be \$77.9 billion (Deloitte Access Economics (2020) The value of informal care in 2020, Carers Australia.
3. Australian Bureau of Statistics (2020) Survey of Disability, Ageing and Carers; Table 13.1.
4. Australian Bureau of Statistics (2020) Survey of Disability, Ageing and Carers; Table 13.1.
5. Australian Bureau of Statistics (2020) Survey of Disability, Ageing and Carers; Table 13.1.
6. With only a small proportion of Victorians with disability eligible for the NDIS, access to the supports it provides is limited to only a small proportion of Victorian carers who support people with disabilities.
7. Australian Bureau of Statistics (2020) Survey of Disability, Ageing and Carers; Table 43.1.
8. Carers NSW (2020) National Carer Survey: Summary Report.
9. The Commission proposed there be systemwide involvement of family members and carers to ensure that in the commissioning mental health and wellbeing services:
 - expectations are set for working with families, carers and supporters;
 - families, carers and supporters are included in a range of therapeutic interventions in each Area Mental Health and Wellbeing Service; and
 - working with families, carers and supporters is part of system-wide workforce training.
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For further information,
please contact

Judith Abbott

Chief Executive Officer
Carers Victoria

T: 1800 514 845

M: 0419 303 130

E: judith.abbott@carersvictoria.org.au

Level 1, 37 Albert Street
(PO Box 2204)
Footscray VIC 3011

www.carersvictoria.org.au

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Carers Victoria acknowledges the Traditional Owners of the land on which we work, the Wurundjeri Woi Wurrung and Bunurong peoples of the Kulin Nation, and pays our respect to Elders past, present and emerging. We acknowledge the continuing connection to land and waters. Sovereignty was never ceded.