# Carers Victoria submission: Victorian State Disability Plan

## Executive Summary

Carers Victoria is genuinely excited by the opportunity to contribute to shaping the next Victorian State Disability Plan.

It is important to us because it shapes the lives of many of our employees, the people governing our organisation, and the carers we serve across Victoria, who themselves often live with disability and/or are in care relationships with others living with disability.

For many people living with disability, the relationships they share with people who support them (their care relationships) are an important source of support that helps them live the lives they choose. These are, for most people on most occasions, relationships that facilitate people with disability fully realising their rights and autonomy. The next Victorian State Disability Plan provides a powerful opportunity to starting actively recognising this.

For the 630,000+ Victorian carers providing support as part of those relationships, having the role they play recognised will be pivotal in making the overall system work better – for people with disability, for the people around them, for communities, and for the broader system of funded supports.

Recognition of carers and the role they plan forms a key element of the Carroll Government's Victorian Carer Strategy 2025-2035 so there is an opportunity to achieve strong policy alignment here.

And actively considering, as part of the next Victorian State Disability Plan, how joint efforts across the disability and carer portfolios can deliver positive and practical improvements for all people in those care relationships offers a powerful opportunity to give practical effect to the Victorian's Government's commitment across the two portfolios.

This submission provides 17 recommendations regarding how that could be achieved. Informed by a diverse range of carer insights and other evidence, opportunities for improvement fall within the existing architecture of the State Disability Plan indicating that the existing systemic reforms and pillars are still relevant.

Fundamentally, we would like to see three key outcomes incorporated into the new State Disability Plan:

1. The criticality of care relationships is recognised, as well as the expertise and needs of carers themselves;
2. The State Disability Plan actively recognises alignment to the Victorian Carer Strategy 2025-2035; and
3. The Plan commits to practical actions that strengthen care relationships.

The next State Disability Plan offers new opportunities, and Carers Victoria looks forward to working alongside government and other stakeholders to realise those opportunities and enhance outcomes for people with disability and others in their care relationships.

## Summary of recommendations

Carers Victoria offers the following recommendations for the new State Disability Plan.[1] Our recommendations also support implementation of focus action areas under the Victorian Government's Carer Strategy 2025-2035 (see Appendix for further details).

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| **Systemic Reforms** |
| 1. Acknowledge carers as critical stakeholders and involve them in service delivery and government advisory processes as a routine part of disability policy development and service design, including a carer with disability being invited to join the Victorian Disability Advisory Council. |
| 2. Genuinely commit to Aboriginal self-determination by ensuring Aboriginal carers have access to culturally safe services. |
| 3. Commit to negotiating a new agreement on the Survey of Disability, Ageing and Carers (SDAC) with the governments of Australia and other states and territories. |
| **Pillar One: Inclusive Communities** |
| 4. Leverage Disability Action Plans by Local Government and other public sector bodies to promote recognition and inclusion of carers. |
| 5. Invest in targeted awareness campaigns about disability and care roles for people in non-specialist roles. |
| 6. Recognise the role of carers and support their contribution in community initiatives. |
| **Pillar Two: Health, Housing and Wellbeing** |
| 7. Recognise and address the needs of the 303,000 Victorian carers with disability. |
| 8. Invest in mandatory training in disability and carer awareness and communication for health care professionals, first responders and other frontline staff. |
| 9. Recognise that carers are often critical partners in the economic inclusion and financial wellbeing of people with disability and address specific financial challenges they both face. |
| 10. Increase the subsidies available through the Victorian Patient Transport Assistance Scheme in line with rising costs and parity with schemes in other jurisdictions. |
| **Pillar Three: Fairness and Safety** |
| 11. Explicitly commit to emergency preparation and recovery planning that includes and responds to the needs of people in care relationships. |
| 12. Support carers with future planning, including advice on legal instruments and supported decision making to avoid people with disability experiencing crisis-driven transitions. |
| **Pillar Four: Opportunity and Disability Pride** |
| 13. Commit to a coordinated, strategic approach to improve system navigation with supports concentrated at key transition points. |
| 14. Ensure the early childhood sector improves acceptance and accommodation for children with disability. |
| 15. Utilise the Thriving Kids initiative and early childhood settings as an opportunity for early identification and proactive outreach to carers of young children with disability to ensure beneficial outcomes for the whole family. |
| 16. Build on disability inclusion reforms in Government schools, ensuring carers are recognised and included as critical stakeholders. Utilise these settings as an opportunity for carer identification and proactive outreach to support transitions for post-school life. |
| 17. Co-design a role for young carers and young people with disability in devising a whole of school approach to addressing discrimination in schools |

[1] For ease of reference, we have also demonstrated where our recommendations would support implementation of focus action areas under the Victorian Government's Carer Strategy 2025-2035 in the text supporting each recommendation.

## About Carers Victoria

Carers Victoria is a for-purpose organisation working to make sure that the almost 1 million unpaid carers across the state are understood, recognised and supported as while it is an important role, it can also be a challenging one. To progress our vision of a future in which all unpaid carers are recognised, valued and supported, we:

- provide them with free advice and information to help them in their role
- connect them to respite activities that allow them to take a break and recharge
- deliver events and education for carers and carer-interested organisations
- collect, analyse and release information about carers so their role and their needs are better understood.

These contribute to our purpose of advancing understanding of Victoria's unpaid carers and improving their access to assistance – whoever they are, wherever they live, and whomever may be in their care relationship/s.

Every Victorian will know, need and/or be an unpaid carer at some point in their lives so the potential reach of our work is significant.

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## Introduction

Carers Victoria welcomes the opportunity to comment on the development of a new State Disability Plan (the Plan). The Plan presents an opportunity to drive life-changing improvements for people with disability across Victoria and to recognise the care relationships that underpin the economic and social participation of many people with disability and often their ability to live in the community.

The new Plan is being developed at a time of significant change in both the disability and aged care systems. Recent reforms arising from the NDIS Review, and changes to the scope of the Scheme, with renewed emphasis on foundational supports and community inclusion, mean that the Victorian government, services – education, health, transport and justice - and the broader community will have a greater role to play in supporting people with disability and their carers.

Unpaid carers will continue to play their critical role, and many are likely to face increasing demand on their time and resources, impacting their own economic and social participation. Changes to the NDIS are happening alongside major reforms to Australia's aged care system. These changes will affect how older people with disability access supports and how disability and aged care services work together.

The *Victorian Carers Strategy 2025-2035* outlines the government's key priorities to deliver on the vision of a different and better future for Victorian carers where they feel recognised, included and supported. The development of a new Plan presents an opportunity to support these priorities, recognising that the rights and wellbeing of many people with disability is interconnected with that of their carers who support outcomes the Plan is trying to achieve.

Carers Victoria appreciates the aspirational vision of an inclusive society with concrete outcomes for people with disability. We believe this vision would be supported by increased recognition of carers in State Government disability policy, as people with needs in their own right. However, carers are missing from the current State Disability Plan creating a significant gap in representation.

Without appropriate reference to and complementarity with the Victorian Carer Strategy, the Plan is likely to perpetuate the invisibility of families and carers whose unpaid work underpins disability, health, mental health and aged care services, as well as mainstream systems like education and housing. Support which cannot be replaced by our mainstream health and social services sectors.

## Achieving systemic reforms: supporting care relationships promotes positive outcomes for people with disability

Unpaid carers commonly provide the most support and assistance to people living with disability (compared to formal services) and are often essential to their health, wellbeing and livelihood, whether they are a child, partner, parent, sibling, other family member, neighbour or friend. The range of care responsibilities often includes personal care, healthcare, transport, advocacy, communication assistance, service navigation, financial, cognitive and/or emotional support, household tasks and behaviour support.

It is estimated that currently, the economic replacement value of the support provided by Victoria's unpaid carers exceeds $18 b per annum in this state alone. However, the worth of unpaid care extends well beyond the economic to the value that unpaid care makes to the lives of the people in care relationships, their communities and broader society.

The legislative basis for carer recognition in Victoria is the *Victorian Carers Recognition Act (2012)* which establishes principles that:

- respect and honour each person in a care relationship and the care relationship itself
- consider the views of each person in a care relationship in the assessment planning, delivery, management and review of services affecting each individual, and the care relationship.

When the health and wellbeing of people in care relationships is supported, relationships become more sustainable and preventable crisis are avoided. People with disability have greater stability and continuity of support in their lives which helps them to maintain autonomy, independence, health and wellbeing as well as participation in community, education and employment.

Recognising the carers of people with disability means acknowledging how an individuals' caring role intersects with their other identities and working to address the practical challenges of disability-related decisions, access barriers, system interfaces and transition points that families and carers manage over time. In addition to their day-to-day caring role, the carers of people with disability may be carrying complex system, legal, housing, health, financial and future planning responsibilities over many years. The right supports provided at the right time can have significant benefits for both carers and the people they support.

For ease of reference, we have demonstrated how each of our recommendations would support implementation of focus action areas under the Victorian Government's Carer Strategy 2025-2035.

### *Recommendation 1: Acknowledge carers as critical stakeholders and involve them in service delivery and government advisory processes as a routine part of disability policy development and service design, including inviting a carer with disability to join the Victorian Disability Advisory Council*

The Plan can be improved by genuine recognition of the role unpaid carers have in the lives of people with disability and embedding their meaningful inclusion in decisions that impact their lives.

Substantial increases in the number of Victorians living with disability across the life course and an ageing population living at home for longer means the number of carers, and the intensity of their care roles are increasing.

Recognition for carers can be achieved without compromising the autonomy or influence of people with disability. While we recognise that there are times where the perspectives of people with disability and their

***Victorian Carer Strategy alignment: Awareness, recognition and respect***

- ✓ People with a care role are recognised, respected and valued.
- ✓ Carers have a say in how services work for them and the people they care for.

carers/supporters may not align, but in our experience this tends to be the exception rather than the rule. Carers usually respect the right of people with disability to exercise autonomy and can play a central role in supporting people with disability to do so by providing wide-ranging assistance to foster their independence and inclusion.

*Recommendation 2: Genuinely commit to Aboriginal self-determination by ensuring Aboriginal carers have access to culturally safe services.*

The Plan should align with Victorian Carer Strategy (2025-35) and specifically commit to recognising and supporting First Nations care relationships.

Findings from the 2024 National Carers Survey show that the majority of First Nations respondents were caring for someone with disability (82.1% of survey respondents). First Nations carers are also more likely to be caring for someone in the absence of any formal support services and 1 in 5 First Nations people with disability are also carers.[2]

A key challenge reported by First Nations carers is getting access to services, particularly culturally safe services that help them feel listened to, valued and empowered with many preferring community-controlled services because these services give them the quality of care they need to feel safe and welcomed.

> *'First Nations carers require services to be culturally safe for themselves, their families and the person(s) they care for. This means having increased access to community-led services, having more First Nations staff at service providers, and ensuring all staff have the cultural competency to support First Nations carers in a way that recognises their history and needs while promoting their dignity and self-determination.*[3]

***Victorian Carer Strategy alignment: Recognise and support First Nations care relationships***

- ✓ First nations communities have what they need to provide self-determined support to people with a care role.
- ✓ Services are culturally safe for First Nations carers and families.
- ✓ Barriers to accessing support for First Nations carers are addressed.

Evidence shows that caring is also a gendered issue (two thirds of primary carers are women[4]), which can have the effect of compounding existing disadvantage for some cohorts.

For example, a 2021 Gari Yala (Speak the Truth) report (Evans 2021) showed how First Nations women in the workplace often experience a 'triple jeopardy' effect due to the compounding effects of racial and gendered inequality and disadvantage due to being a carer.

*'All unpaid carers should at the very minimum have workplace rights, where they are able to request flexible working arrangements and be supported by employers. ATSI women are vulnerable in the workplace to discrimination, and this is exacerbated at any time they have carer responsibilities.'*

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[2] Australian Bureau of Statistics (25 February 2025), Aboriginal and Torres Strait Islander peoples with disability, 2022, ABS Website, accessed 28 August 2026.
[3] First Nations Carers in the National Carer Survey Report, October 2025, p.28
[4] SDAC Disability, Ageing and Carers, Australia: Summary of Findings, 2022 | Australian Bureau of Statistics

*Recommendation 3: Commit to negotiate a new agreement on the Survey of Disability, Ageing and Carers (SDAC) with the governments of Australia and other states and territories.*

The Plan is an opportunity for the Victorian Government to reaffirm its commitment to capturing data about the prevalence of people with disability, their carers and families and insights into their lived experience.

A new agreement on the SDAC would ensure this is undertaken every three years and the data collected is reliable for smaller geographies, not just at the national level.

We note the Victorian and Australian Governments are focused on measuring outcomes of their respective disability strategies and service delivery. However, Carers Victoria believes high-quality statistics on the prevalence of disability across the life course and carers nationally continue to play an important role in knowing the whole picture related to planning and designing services for people with disability and carers and assessing how disability plans can be measured and improved.

***Victorian Carer Strategy alignment: How we will track progress***

- ✓ 'We will work with organisations that have important data to help better understand the experiences of carers, the people they care for and the systems they use.' (p.31)

The SDAC has been collected since 1981, along with critical information on access to disability services, experience of discrimination, social participation, health and wellbeing and is not limited to NDIS participants (noting this cohort represents approximately 15% of the estimated number of Australians with disability and excludes those over the age of 65 who were not eligible for the Scheme prior to this age).

A reliance on data from service recipients risks a partial and deficient picture, relying only on people who use services, disclose their disability or are confident to participate in research to be counted. One example is health service data which relies on patients with disability or their carer to disclose their disability status. This being a voluntary identifier means health service data doesn't provide a complete picture.

## Pillar one: Inclusive communities

### Recommendation 4: *Leverage Disability Action Plans by Local Government and other public sector bodies to promote recognition and inclusion of carers*

Disability Action Plans of public sector bodies and local governments, as mandated by the Disability Act (2006), should be leveraged to better recognise and include people with disability and their carers to design place-based person-centred services. Carers have shared multiple examples of where there are opportunities to enhance inclusion:

- A lack of sensory rooms and quiet hours to everyday local infrastructure such as pools, libraries, shopping centres and local parks.
- In regional areas, service models that assume travel carers cannot always do, especially in areas where digital delivery is not a reliable substitute because internet and mobile coverage is poor.
- The standard playground swing with a rubber seat and chain across, which offers little to a child with low muscle tone or poor head control.

- The Get Active Kids voucher program which depends on individual centers signing up, so it does not reach families whose local center has not.

Social connectedness is a significant contributing factor to the health and wellbeing of people in care relationships. This is exacerbated for carers living in regional and rural areas as they do not always have the capacity, the time, or the financial means, to travel to participate in programs that are further away from home[5].

Councils provide local infrastructure and community facilities valued at over $110 billion across Victoria. Despite this significant budget, Councils are often underestimated in their potential to foster local community connections.

The Plan should encourage public sector bodies and local government to proactively engage with people with disability and carers, consistently incorporating their needs in the development and delivery of council services.

***Victorian Carer Strategy alignment: Awareness, Recognition and Respect***

- ✓ Communities and services understand the diversity of care roles and relationships.

***Quality services, at the right place, at the right time***

- ✓ People with a care role and their families are supported as early as possible.
- ✓ Services are easy to find and access for carers, no matter where they live.

***Participation, Connection and community***

- ✓ Carers have opportunities for social, cultural and community connection.

### Recommendation 5: *Invest in targeted awareness campaigns about disability and care roles for people in non-specialist roles*

Carers describe how the interactions they find the hardest are most often with people who are not disability specialists.

Community awareness about disability is critical to inclusion and carers want to see disability and autism awareness training beyond the specialist workforce, including retail and centre management, security, cleaning, administrative and pathology staff included in the new State Plan[6].

***Victorian Carer Strategy alignment: Awareness, Recognition, Respect***

- ✓ People with a care role are recognised, respected and valued.
- ✓ Communities and services understand the importance and diversity of care roles and relationships.

### Recommendation 6: R*ecognise the role of carers and support their contribution in community initiatives*

Community awareness and genuine inclusion for people with disability in community activities can also provide a respite effect for carers.

This effect is heightened when community initiatives recognise the role of carers in enabling participation for people with disability.

For example, parking and public transport discounts, expanding companion card eligibility and Victorian Carers Card discounts recognise

[5] 63% of carers report feeling highly isolated and their wellbeing is significantly lower (at 56%) compared to people not in a care role.
[6] Carers Victoria State Disability Plan consultation report, 2026

carer's contribution and can help reduce costs when supporting people with disability in community activities.

## Pillar two: Health, Housing and Wellbeing

### *Recommendation 7: Recognise and address the needs of the 303,000 Victorian carers with disability*

The barriers to health care for people with disability were explored in detail by the Disability Royal Commission, with a particular focus on health care for people with cognitive disability, autism and intellectual disability.

To enhance health, housing and wellbeing outcomes, the Plan must recognise and address the needs of carers with disability – of which there are more than 300,000 Victorians (or 20% of the population of people with disability).

A mutually exclusive approach to disability and caring limits visibility of these individuals' needs within health settings when professionals don't consider disability and a care role in tandem.

Carers with disability have described being treated as the carer at every point of contact with services, rather than as a person who may also need support. As a result, these carers often remain hidden as service users, resulting in ineffective assessment and inadequate service delivery.

***Victorian Carer Strategy alignment: Awareness, Recognition and Respect***

- ✓ People with a care role are recognised, respected and valued
- ✓ Carers have a say in how services work for them and the people they care for.
- ✓ Communities and services understand the importance and diversity of care roles and relationships

***Quality services, at the right place, at the right time***

- ✓ People with a care role and their families are supported as early as possible.
- ✓ Services are easy to find and access for carers, no matter where they live.

### *Recommendation 8: Invest in mandatory training in disability and carer awareness and communication for health care professionals, first responders and other frontline staff.*

Carers report ongoing experiences of stigma and discrimination against people with disability in the health system and emphasise the need for increased public awareness and education. They highlight the importance of mandatory training (for example in dementia awareness) for healthcare professionals, first responders and other frontline staff to improve safety, and care quality.

For the Plan to achieve better health outcomes, health services should actively include carers by:

- routinely identifying and involving them in care and discharge planning,
- providing referral pathways to carer supports, and
- at a systemic level, including them in program design, review and advisory functions.

This is important for the Plan because carers can be key partners in healthcare for people with disability if they are appropriately involved and supported to carry out their caring role.

Carers express frustration that they are often not consulted or ignored altogether when trying to advocate for the person they care for to ensure their safety and appropriate treatment. By recognising in the next plan that carers can be key partners in healthcare for people with disability if they are appropriately involved and supported to carry out their caring role, the Victorian Government can actively tackle this challenge for carers – and in doing so deliver better outcomes for the individual and the system.

Existing Victorian initiatives such as the Disability Liaison Officer program in health services and models supporting carers in health service partnerships could be extended to also provide referral pathways to carer supports at key intake points in the health system for people with disability.

Supporting health services to routinely involve carers in care and discharge planning for people with disability, would recognise the critical role they often play in ongoing health management and improve outcomes for people with disability.

Case example: becoming a carer overnight. A [consultation] participant became a full time carer within the last year, when her husband was diagnosed with Parkinson's disease. He was discharged from hospital with no explanation of the condition or of what she could do. No one in her family had been a carer before and no one had Parkinson's, so she had no informal knowledge to draw on. She researched it herself. Several months later she was connected to a peer support group, which is where she says she got information. His specialist appointments run for fifteen minutes every six months.

> *"After he was discharged from the hospital, there was no one to even tell me what Parkinson's is. How do you… what are the steps that you can do as a… carer? … At [the] hospital they see him for 15 minutes every six months. So what do you learn from there?"*

Case example: eight years without a handover**.** A [consultation] participant cares for her son, who has an acquired brain injury, vision impairment, memory loss, anxiety and behaviours of concern. He was discharged from the Royal Children's Hospital when he turned 18. In the eight years since, she has been trying to obtain an appointment with a neurologist through the public system. English is her second language, which she says makes the paperwork and the following up harder again. She described managing health, disability and support systems at once as very difficult.

Case example: Young carers need support to manage the practical, emotional and psychological challenges of their role**.**

Young carers report feeling invisible in health services and support systems despite often having significant caring responsibilities. Young carers' experience highlights the importance of paying attention to and supporting family relationships which are often critical to the wellbeing of people with disability and help make a good life. Young carers tell us that they want to help their siblings or parents with disability, but to do so, they themselves need support to manage the practical, emotional and psychological challenges of their role.

As a start, young carers have proposed mandatory training for health professionals and disability support workers on the role of young carers to ensure they are recognised and appropriately supported. We offer further proposals for how young carers could help

address discrimination against young people with disability under the section on education.

## Financial wellbeing

*Recommendation 9: Recognise that carers are often critical partners in the economic inclusion and financial wellbeing of people with disability and address specific financial challenges they both face.*

The number of carers experiencing financial stress has doubled since 2020 with 62% of carers experiencing financial stress compared to 49% of the population who don't have care roles.

One in three carers spend more than they receive and many don't have the financial resources to manage unexpected bills or costs. For young carers, the cost of caring across the household can impact the household's financial security and home learning environment, significantly impacting their educational and wellbeing outcomes.

The current cost of living crisis in Australia is exacerbating the financial precarity many face and these pressures are particularly acute for carers who have had to reduce their hours or withdraw entirely from paid employment due to their caring role[7].

***Victorian Carers Strategy alignment: Participation, Connection and Opportunity***

- ✓ People with a care role have greater financial security.

Financial Counselling Victoria points out that this is an important consideration for the State Plan because the finances of people with disability are often interconnected with that of their families and carers. As such, financial wellbeing needs to be considered holistically in disability policy with carers needing access to timely information, advice and specialist supports to build financial resilience alongside the people they care for[8].

*Recommendation 10: Increase the subsidies available through the Victorian Patient Transport Assistance Scheme in line with rising costs and parity with schemes in other jurisdictions.*

People in care relationships in regional and rural areas face greater barriers when it comes to accessing essential medical care. When services are not available locally, patients and carers must travel long distances to access the care they need. This travel can be expensive, frequent and unavoidable.

For some, the financial burden may lead to people avoiding or delaying treatment or accessing less optimal care close to home. This is concerning, as regional Victorians with disability experience poorer health outcomes, with higher rates of cancer, chronic disease and mental health issues, compared to people living in metropolitan Melbourne.

Carers have described services that often assume travel they cannot always undertake. One carer in Gippsland described services expecting carers and care recipients to travel to them, in an area served by two buses a day that do not connect with the trains, where poor internet and mobile coverage also limits digital alternatives.

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[7] The long-term impact of caring on income and superannuation is significant with an average of $392,500 in forgone income by age 67 for primary carers

[8] Financial Counselling Victoria Submission to the State Plan

*'Services expect carers and their care recipients to travel to the services all the time. We have a very limited public transport service… there's two buses a day. Which don't line up with the trains.'*[9]

The Victorian Patient Transport Assistance Scheme is designed to reduce the financial burden associated with this travel. However, the scheme has not kept pace with rising costs or patient needs, contributing to inequitable access to care[10].

## Pillar Three: Fairness and safety

### *Recommendation 11: Explicitly commit to emergency preparation and recovery planning that includes and responds to the needs of people in care relationships.*

Emergencies such as the 2026 summer bushfires are not single events, rather they are indicative of a changing climate with extreme weather becoming more frequent and severe. In response, we need emergency planning to explicitly respond to the needs of people in care relationships, particularly harder to reach cohorts, and long-term investment in community-led adaptation, resilience, and recovery.

There are some excellent preparedness and planning resources that can help households prepare for emergencies (such as the Red Cross RediPlan), but carers are often too exhausted, time-poor or overwhelmed to fill them out. Similarly, early warning systems, evacuation procedures and centres, and emergency recovery initiatives will not work if they have been designed without the specific needs of carers and people with disability in mind.

For example, during the 2026 bushfires, carers in the Mount Alexander Shire reported the disproportionate impact of being unable to access allied health and home care supports that they usually relied on to sustain their role. While emergency protocols prioritised some essential services, there are some supports that don't meet this definition such as respite, personal care, and specialist interventions that are essential to safely sustain a care role. Without access to these supports, carers and the people they care for experience poorer health outcomes and increased risk, and isolation.

People with mobility, health care and/or behavioural needs and their carers often have greater reliance on energy and water utilities (for example washing clothes and bedding, life support systems, refrigeration for medications, monitoring systems and heating or cooling), as well as essential services like communications and transport. Emergency management agencies need to facilitate access to these critical supports as soon as possible after the initial threat has passed to ensure the health and wellbeing of people with disability and their carers.

Disability awareness training for staff and volunteers in evacuation centres is essential and it should incorporate carer awareness so that staff have an understanding of the additional challenges they may be dealing with during an emergency. This could mean having information about supports available for carers at evacuation centres, providing contact information and facilitating access to IT if needed to enable access.

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[9] Carers Victoria Consultation report for State Disability Plan 2026

[10] Victoria offers the lowest subsidies for private vehicle travel (21c/km) and accommodation ($45p/n) in the country.

*Recommendation 12: Support carers with future planning, including advice on legal instruments and supported decision making to avoid people with disability experiencing crisis-driven transitions.*

All carers need support for their own needs and help with planning to ensure the future health and wellbeing of people with disability they care for; however, older carers – particularly those who have been caring for decades – are particularly vulnerable when navigating complex service systems and legal and financial requirements.

More than 197,000 Victorian carers are aged 65 and over. Many of these older carers acquire disability as they age and describe transitions arriving faster than they can plan for them. Older carers carry a lot of anxiety about what happens when they can no longer continue in their care role.

For carers of adults this is a major and long-standing concern and Carers Victoria has advocated for family-centred future planning services from both the Victorian and Commonwealth Governments.

***Victorian Carers Strategy alignment: Quality services in the right place, at the right time***

- ✓ People with a care role and their families are supported as early as possible.
- ✓ Services are easy to find and access for carers, no matter where they live.

The anxiety carers describe has concrete implications for the lives of people with disability whom they support. For example, a carer aged 78, supporting a son of 49, described planning for her own incapacity without assistance, and without any informal network to hand responsibility to. She recalled being told by NDIS staff to plan for the future and delegate.

> *'The staff say, look… you've got to think of the future and try and delegate, but there's no one to delegate to'*

Additional pressing issues for adults with disability who have older carers are understanding legal instruments such as emergency care plans, powers of attorney, guardianship, housing, special disability trusts and the role of State Trustees that may be needed to support a care recipient when their carer can no longer support them. Older carers have told us they need more guidance and a single place or repository that covers all of these things in a simple, cohesive way.

Carers would also benefit from clear, accessible support to understand contemporary supported decision-making principles and other issues such as when guardianship is inappropriate or unnecessarily restrictive for people with disability. Practical guidance, education and access to independent advice can help carers distinguish between providing support and taking over decision-making, while also recognising the complex responsibilities and concerns that carers are facing.

We offer further recommendations to aid future planning under the section on system navigation in Pillar four.

## Pillar Four: Opportunity and Disability Pride

*Recommendation 13: Commit to a coordinated, strategic approach to improve system navigation with supports concentrated at key transition points.*

This Pillar's focus on education, training and work should be underpinned by co-designed systemic improvements to service navigation that support carers, provide opportunities to better connect them to their peers and gives them the right information at the point when they need it.

In consultations for the new Plan, carers described the work involved with trying to make health, housing, disability, aged care and education systems operate together in a person's life.

Even carers with strong skills and knowledge find it difficult. However, carers often say that their need for information and support is not constant. Rather, the need is concentrated at key transition points which can be anticipated- from first diagnosis, to moving between systems and at key life transitions:

- The start of a caring role: At diagnosis, or at hospital discharge. This is where care relationships tend to start, it is also where a carer might identify as such and seek support, or not.
- To a different form or intensity of care: such as when an adult with disability moves out of the family home or into supported accommodation, or when a carer leaves paid work and their caring role expands into it.
- When a person with disability moves between systems: from paediatric to adult health, from school to training or work, from NDIS to residential aged care.
- When the carer comes to need care themselves: ageing carers consistently describe their anxiety about what will happen to the person they care for when they can no longer sustain their role.

***Victorian Carer Strategy alignment: Quality services in the right place, at the right time***

- ✓ People with a care role and their families are supported as early as possible.
- ✓ Services are easy to find and access for carers, no matter where they live.
- ✓ Services work together to provide flexible, connected support.

The Plan should commit to a coordinated, strategic approach to system navigation. This should involve consultation with people with disability, carers and relevant peak organisations to map the information, service and support gaps that arise at key life stages and predictable transition points to inform the design of practical responses that provide the right support at the right time.

### Early childhood

*Recommendation 14: Ensure the early childhood sector improves acceptance and accommodation for children with disability*

Pleasingly, there has been much investment in the Victorian early childhood sector since 2022 when the current Government announced the Best Start, Best Life reforms, providing access to free kinder for three and four year old children as well as establishing 50 centres in areas with unmet demand.

The Kindergarten Inclusion Support Program is also a welcome addition to ensure Victorian-funded centres are responsive to the needs of children with a disability, developmental delay or complex medical needs.

However, carers continue to describe challenges with accessing support through the early childhood sector with many private practitioners and/or centers not willing to accept children with disability. One carer's youngest child was excluded from three childcare centers in a single year, while attending a sessional kindergarten in the same period without incident.

Carers value services that make structural adjustments rather than individual accommodations, naming a community childcare center with a disability action plan that installed acoustic paneling to reduce noise as a positive example.[11]

With changes to the regulation of the early childhood sector, the Plan is an opportunity to embed further practical changes to ensure all early childhood providers can respond to the needs of children and their carers.

### *Recommendation 15: Utilise the Thriving Kids initiative and early childhood settings as an opportunity for early identification and proactive outreach to carers of young children with disability to ensure beneficial outcomes for the whole family*

Carers of young children describe the early years as the period in which a family either connects with support or does not, with flow on implications for their child's lifetime outcomes.

*"It has taken me two years to even hear about things like My Time, or the carers card, these sort of basic things which help. And then when I tell other people, including the maternal child health nurse, the physio, they're like, never heard of that."*

Carers have a critical role to play in supporting their child's development and wellbeing. Actively including carers including young carers in planning, goal setting and service coordination will lead to better outcomes for children with disability and their families and this holistic approach should be integral to early childhood and school-age disability supports under Thriving Kids.

There is now strong research revealing that by Year 9, children with care roles of 5 hours per week are, on average, one year behind the education standards of their peers who don't have care responsibilities.

These poorer educational outcomes begin as early as primary school. Part of the reason is that these children are also more likely to have experienced financial disadvantage throughout their childhood.

The authors suggest that young carers experience a "considerable negative influence on their cognitive outcomes" by virtue of living in a household with people with care needs and/or having a parent with a high level of caring responsibilities for another household

[11] Carers Victoria consultation report for the State Disability Plan 2026

member, and the subsequent impacts on the household's financial security and home learning environment."[12]

Victoria has extensive experience in implementing a family-centred early intervention approach through the specialist ECIS program with supports designed to strengthen the capability of the whole family such as by providing coaching and practical strategies to help parents support their child's communication, behaviour and participation in everyday activities in the home.

A family centred approach might also include better support for children and families through key transitions, such as starting kindergarten, school, or moving between service systems with coordinated planning that considers both the child's needs and the capacity and wellbeing of their parents and carers.

The Victorian Government's current proposed model for Thriving Kids would embed disability supports for children birth to eight years old in the Maternal Child Health and early childhood education system.

We recommend this model includes development of, and resourcing for, carer support groups and referral pathways to existing carer supports, and that these services are offered to all parents/carers of children with disability, not just those at risk of involvement with the Child Protection system.

***Victorian Carer Strategy alignment: Quality services in the right place, at the right time***

- ✓ People with a care role and their families are supported as early as possible.
- ✓ Services are easy to find and access for carers, no matter where they live.
- ✓ Services work together to provide flexible, connected support.

## Primary and secondary education

*Recommendation 16: Build on disability inclusion reforms in Government schools, ensuring carers are recognised and included as critical stakeholders. Utilise these settings as an opportunity for carer identification and proactive outreach to support transitions for post-school life.*

As noted above, there have been many welcome reforms that support Government schools to respond to the needs of children with disability extending to primary and secondary education; however, there continue to major gaps reported by carers.

Despite such significant reforms, carers of school aged children with disability have described an education system that offers nothing for children whose disability means they don't qualify for mainstream schools but do not qualify for specialist schools.

*'She] doesn't qualify to go into a mainstream school because of her intellectual disability. However she's also an extremely social child that needs lots of people, lots of chat, lots of everything. So she doesn't suit other SDS schools where… there's very high needs… So there was nothing that we could find in that sort of middle ground, and then going to high school, even less.'*

[12] Warren, D., & Edwards, B. (2025). Young carers: Impacts of caring on children's learning and wellbeing. Melbourne: Australian Institute of Family Studies, page 6.

Carers consistently tell us that options for children with disabilities thin sharply after primary school resulting in:

- variable, or minimal school attendance for some children that struggle with the school environment
- shortened or disrupted school days (and shorter school terms for some specialist schools)
- detrimental impacts on learning and social opportunities. For example, one carer described her son in a mainstream setting spending three hours of school time in the wellbeing hub with an education support staff member, with no class learning or peer interaction. Another described her son as *'the child who never gets invited to birthday parties- it breaks your heart'*

Parents and carers have requested information about which schools can accommodate which needs including what support is actually available in the classroom, with carers observing that choosing the right secondary school for their child is difficult without it.

***Victorian Carer Strategy alignment: Participation, connection and opportunity***

✓ Workplaces, study and school environments are carer friendly.

***Quality services in the right place, at the right time***

✓ People with a care role and their families are supported as early as possible.

*'I would have liked to have been able to go to a website with [a] list of, like, these are five schools in your area… Because it's a lot of responsibility. Trying to pick a high school.'*

In addition to the impact these challenges have on educational outcomes for children with disability, the lack of structure in the day-to-day life of a family and limited to no access to services that other parents take for granted, such as holiday and before/after school programs, has a direct impact on parents and carers' ability to maintain employment or a life outside of their parental/caring role. We note there has been investment in the High Intensity Outside School Hours Care Initiative for students with disabilities with funding to 30 schools this year.

Carers have also raised the pressures of school attendance policy, describing families sustaining partial attendance for a child who cannot manage a full day being recorded as underperforming, whereas from their perspective their child's sustained partial attendance was a win not a failure.

*'We average 70% attendance rate and I am proud of that, the school thinks we can do better.'*

Carers Victoria fully supports the State Government's commitment to ensuring the best educational outcomes for every child, but a more constructive approach would be to further consider barriers to inclusion that may be preventing the child from attending school and/or if additional supports are needed to support a family to lift school attendance rather than a deficit lens.

*Recommendation 17: Co-design a role for young carers and young people with disability in devising a whole of school approach to addressing discrimination in schools*

Stigma remains a primary barrier to disability pride and inclusive education. In reporting on their own experiences at school, young carers raised concerns about what they perceived as low expectations from educators and other forms of discrimination they witness against their siblings with disability at school.

'*My sister still knows when other people are looking down on her and that makes her less included to go out and do things*'

We need to think outside traditional disability/carer policy demarcations to help address these challenges. If given the right support, young carers may be uniquely placed to help address disability discrimination in the school environment while simultaneously raising awareness about young carers and their role.

An effective strategy to assist young people in care relationships to thrive in education settings may be a whole of school approach where solutions are designed together by young carers, students with disability, teachers and the wider school community to assist young people in care relationships to thrive in education settings and support their aspirations beyond school.

***Victorian Carer Strategy alignment: Participation, connection and opportunity***

- ✓ Workplaces, study and school environments are carer-friendly.
- ✓ Carers have opportunities for social, cultural and community connection.

## Conclusion

The new State Disability Plan can strengthen inclusion, participation and wellbeing for people with disability by recognising that their families and carers are a normal and beneficial part of many people's lives.

Carers Victoria urges the Victorian Government to explicitly recognise unpaid carers in the State Disability Plan, align its commitments with the Victorian Carer Strategy and invest in practical actions that support people with disability and carers at the points where systems, services and life transitions place the greatest pressure on care relationships.

Doing so will help build a more inclusive Victoria in which people with disability and their carers are recognised, supported and treated with dignity and respect.

Carers Victoria looks forward to contributing to achievement of that aspiration.

## Appendix

| Victorian State Disability Plan recommendations | Victorian Carer Strategy Alignment |
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| **Systemic Reforms** | |
| 1. Acknowledge carers as critical stakeholders and involve them in service delivery and government advisory processes as a routine part of disability policy development and service design, including a carer with disability being invited to join the Victorian Disability Advisory Council. | *Awareness, recognition and respect*<br>✓ People with a care role are recognised, respected and valued.<br>✓ Carers have a say in how services work for them and the people they care for. |
| 2. Genuinely commit to Aboriginal self-determination by ensuring Aboriginal carers have access to culturally safe services. | *Recognise and support First Nations care relationships*<br>✓ First nations communities have what they need to provide self-determined support to people with a care role.<br>✓ Services are culturally safe for First Nations carers and families.<br>✓ Barriers to accessing support for First Nations carers are addressed. |
| 3. Commit to negotiating a new agreement on the Survey of Disability, Ageing and Carers (SDAC) with the governments of Australia and other states and territories. | *How we will track progress*<br>✓ 'We will work with organisations that have important data to help better understand the experiences of carers, the people they care for and the systems they use.' (p.31) |
| **Pillar One: Inclusive Communities** | |
| 4. Leverage Disability Action Plans by Local Government and other public sector bodies to promote recognition and inclusion of carers.<br>5. Invest in targeted awareness campaigns about disability and care roles for people in non-specialist roles. | *Awareness, Recognition and Respect*<br>✓ Communities and services understand the diversity of care roles and relationships. |

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| | *Quality services, at the right place, at the right time*<br>✓ People with a care role and their families are supported as early as possible.<br>✓ Services are easy to find and access for carers, no matter where they live.<br><br>*Participation, Connection and community*<br>✓ Carers have opportunities for social, cultural and community connection. |
| 6. Recognise the role of carers and support their contribution in community initiatives. | *Awareness, Recognition, Respect*<br>✓ People with a care role are recognised, respected and valued.<br>✓ Communities and services understand the importance and diversity of care roles and relationships. |
| **Pillar Two: Health, Housing and Wellbeing** | |
| 7. Recognise and address the needs of the 303,000 Victorian carers with disability.<br>8. Invest in mandatory training in disability and carer awareness and communication for health care professionals, first responders and other frontline staff. | *Awareness, Recognition and Respect*<br>✓ People with a care role are recognised, respected and valued<br>✓ Carers have a say in how services work for them and the people they care for.<br>✓ Communities and services understand the importance and diversity of care roles and relationships<br><br>*Quality services, at the right place, at the right time*<br>✓ People with a care role and their families are supported as early as possible. |

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| | ✓ Services are easy to find and access for carers, no matter where they live. |
| 9. Recognise that carers are often critical partners in the economic inclusion and financial wellbeing of people with disability and address specific financial challenges they both face. | *Participation, Connection and Opportunity*<br>✓ People with a care role have greater financial security. |
| 10. Increase the subsidies available through the Victorian Patient Transport Assistance Scheme in line with rising costs and parity with schemes in other jurisdictions. | |
| **Pillar Three: Fairness and Safety** | |
| 11. Explicitly commit to emergency preparation and recovery planning that includes and responds to the needs of people in care relationships. | *Quality services in the right place, at the right time*<br>✓ People with a care role and their families are supported as early as possible.<br>✓ Services are easy to find and access for carers, no matter where they live.<br>✓ Services work together to provide flexible, connected support. |
| 12. Support carers with future planning, including advice on legal instruments and supported decision making to avoid people with disability experiencing crisis-driven transitions. | |
| **Pillar Four: Opportunity and Disability Pride** | |
| 13. Commit to a coordinated, strategic approach to improve system navigation with supports concentrated at key transition points. | *Quality services in the right place, at the right time*<br>✓ People with a care role and their families are supported as early as possible.<br>✓ Services are easy to find and access for carers, no matter where they live.<br>✓ Services work together to provide flexible, connected support. |
| 14. Ensure the early childhood sector improves acceptance and accommodation for children with disability. | |
| 15. Utilise the Thriving Kids initiative and early childhood settings as an opportunity for early identification and proactive outreach to carers of young children with disability to ensure beneficial outcomes for the whole family. | *Quality services in the right place, at the right time*<br>✓ People with a care role and their families are supported as early as possible. |

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| | ✓ Services are easy to find and access for carers, no matter where they live.<br>✓ Services work together to provide flexible, connected support. |
| 16. Build on disability inclusion reforms in Government schools, ensuring carers are recognised and included as critical stakeholders. Utilise these settings as an opportunity for carer identification and proactive outreach to support transitions for post-school life. | *Participation, connection and opportunity*<br>✓ Workplaces, study and school environments are carer friendly.<br>*Quality services in the right place, at the right time*<br>✓ People with a care role and their families are supported as early as possible. |
| 17. Co-design a role for young carers and young people with disability in devising a whole of school approach to addressing discrimination in schools | *Participation, connection and opportunity*<br>✓ Workplaces, study and school environments are carer-friendly.<br>✓ Carers have opportunities for social, cultural and community connection. |