



**Carers Victoria submission:**

**Victorian State Disability Plan  
2017 – 2020**

**6 July 2016**

**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

# About Carers Victoria

Carers Victoria is the state-wide peak organisation representing people who provide unpaid care. We represent more than 700,000 family carers across Victoria including people caring for ageing parents, children with disabilities, and partners with chronic or mental illness.

Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

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# Introduction

Carers Victoria welcomes the opportunity to respond to the Victorian Government Discussion Paper and Companion Document for the Victorian State Disability Plan 2017 – 2020. These documents explore four key themes - active citizenship, rights and equality, economic participation and making the most of the NDIS.

Carers Victoria believes the Victorian State Disability Plan 2017 - 2020 is an opportunity for the Victorian Government to broaden its social justice and equality agenda to improve the rights, health, wellbeing and life chances of over 13 percent of Victorians who are carers (ABS, 2014), many of who also make up a proportion of the 20 percent of the population with a disability (ABS, 2014).

Relevant to the Government's equality agenda are two issues present in carer research. The first is 71 percent of all primary carers are women (Carers Victoria, 2016 p.9). This fact contributes significantly to gender gaps in employment and other social and economic outcomes (such as further education, superannuation and home ownership), as well as the health and wellbeing of a significant cohort of women.

The second issue is there are specific communities with significantly high rates of carers we are statistically or anecdotally aware of, yet they remain 'hidden' to many service providers and policy makers. These communities include Aboriginal and Torres Strait Islander (ATSI), Culturally and Linguistically Diverse (CALD), Refugee and Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) communities.

Carers from these communities are yet to be substantially incorporated within research and data collection. They also have special needs due to intersections of marginalisation. By this we mean, in addition to barriers they face as carers, these populations face disadvantage as a result of indirect or direct discrimination, and community stereotypes due to attributes beyond their carer status. Consequently they may experience poor carer identification by others, or they may not self-identify with the carer label themselves. They can also be less likely to seek help from services.

Some facts we know about these populations are:

- 25-30 percent of carers in Australia are estimated to be from CALD backgrounds (Carers Australia, 2016).
- 12.4 percent of the Aboriginal and Torres Strait Islander population are carers, compared to 10.5 percent of the non-Indigenous Australian population (AIHW and ABS, 2008 p. 70). This is likely to be linked to higher prevalence overall of disability, mental illness and chronic disease among Aboriginal and Torres Strait Islander people than other Australians (AIHW and ABS, 2008 p. 60).
- Private Lives 2 survey identified 30 percent of LGBT respondents classified themselves as current carers (Leonard, et al. 2012, p. 24). Specifically relevant to the LGBTI experience of caring is the history of stigma, particularly among older people who suffered the criminalisation of homosexual relationships and transgender expression (Barrett & Cramer, 2015 p. 1); as well as the high levels of mental illness among LGBTI communities (Rosenstreich, 2013 p. 3).

Similarly, young people also remain an un-recognised cohort of carers. While there is some research and awareness of young people in care relationships with others such as siblings and parents with a disability, identification and inclusion of these young people is systemically poor (Carers Australia, 2002 p.15).

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## About Carers and Care Relationships in Victoria

Over 773,400 people in Victoria are carers with 217,800 of these Victorians identified as 'primary carers'. This refers to the key role they play in providing the majority of assistance to a person / or persons with communication, mobility and self-care. Thirty-five percent of primary carers spend on average 40 hours or more per week providing care (ABS, 2014).

When Carers Victoria refers to 'carers', we mean those people who identify themselves as carers, and those who are identified by service providers as having a carer role. We also recognise carers who have not been identified by themselves or others (hidden carers). It is Carers Victoria's view regardless of how people identify, a person's caring responsibilities create specific needs and unique vulnerabilities to their health and wellbeing.

When we refer to 'family' we acknowledge that family relationships are diverse, unique and the term 'family' can mean different things to different people. Families as we refer to them encompass families of choice as well as biological families and these can include partners, friends, kin or neighbours.

A report by the Australian Institute of Health and Welfare (AIHW) identified the numbers of people with a disability living in the community has increased (2008 p. 28). Most people with a disability live with family or friends. The report also stated of all people with a severe or profound disability aged between 5 and 65 (2008, p. 29):

- 2.5 percent lived in cared accommodation
- 84 percent lived with family
- 3.2 percent lived with unrelated people, probably friends, and
- 10 percent lived alone in the community

The sustainability of specialist and mainstream disability services and supports is reliant on the care provided by families and friends. The needs of and outcomes for people with a disability are inextricably linked with people who are in care relationships with them. Family members or friends assist more than 292,100 Victorians with a severe or profound disability. It has been estimated that unpaid family and other informal care accounts for approximately 74 percent of the support provided to older people and persons with a disability in Australia (Allen Consulting Group, 2007).

## A whole of government Victorian Carers Strategy

Carers Victoria supports the creation of a whole of government Victorian Carers Strategy to complement and coincide with the planning, development and implementation of relevant initiatives set out under the Victorian State Disability Plan 2017 – 2020, the Ten Year Mental Health Plan and other departmental plans covering a range of areas that intersect with carer needs.

A Victorian Carers Strategy would apply to the needs of individuals who support people with a disability, a mental, chronic or terminal illness, and/or drug and alcohol addiction; or people who have an aged related disability or illness.

The priority of a Victorian Carers Strategy is to direct policy actions that ensure all carers are respected, valued and supported, and have the same rights, choices and opportunities as other members of the community. It would also assist to provide some further carer specific directives around initiatives designed to support Victorians eligible for the NDIS.

The Carer Recognition Act 2012 followed by the development of the Victorian Carer Action Agenda in 2014 set a precedent for positive action around carer needs. To date the Carer Action Agenda has not been implemented and as time has passed the NDIS has influenced service-scape shifts resulting in dynamic and rapid sector change. Carers Victoria sees an urgent need for attention to the three areas identified in the Carer Action Agenda and more.

A Victorian Carer Strategy will provide a more comprehensive response to the needs of people in care relationships who require ongoing support services to assist them navigate the disability, health and mental health sectors and to address their own needs.

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## Key General Points

There are a number of key points Carers Victoria would like to raise before discussing the four themes in the Discussion Paper and Companion Document.

Firstly, Carers Victoria would like to see inclusion of the following groups in the Victorian State Disability Plan 2017 - 2020:

- carers and caring families (including within this definition - caring biological families/families of choice, young carers, partner carers, friend and neighbour carers)
- inclusion of people with a psychosocial disability
- the approximately 33 percent of carers that have a disability themselves (ABS, 2013)
- carers of people with a drug and alcohol related disability such as an acquired brain injury or alcohol-related dementia, and
- people with disabilities over the age of 65.

We would also like to see the proposed Victorian State Disability Plan 2017 - 2020 themes linked to Victorian Government responsibilities in key relevant areas to ensure a consistent, more holistic implementation of the Plan and broader societal impact. Some of these key areas include health, mental health, justice, education, transport, housing and welfare.

Carers Victoria believes the documents provided to date are overarching, and represent an overall framework rather than a 'plan'. Gaps in service accessibility and poor outcomes in a variety of life's domains for people with disabilities need to be identified and linked to specific actions, measurable outcomes, impact measures and joint policy initiatives.

We would like to see specific and separate implementation plans containing aims, actions, performance indicators, goals, and timelines outlining responsibilities under each theme. This would reassure people with disabilities and those in care relationships with them that the Government is committed to measurable outcomes in these four areas.

Carers Victoria recommends a whole of policy approach. Aims, goals and actions that address carer issues should also be identified and incorporated where possible within initiatives that sit beneath other related overarching strategies and frameworks, such as the Ten Year Mental Health Plan and the Victorian Public Health and Wellbeing Plan.

**Recommendation:** Department of Premier and Cabinet takes leadership for developing a whole of government Statewide Victorian Carer Strategy through consultation, collaboration and co-design.

**Recommendation:** The Victorian Carer Recognition Act 2012 and the National Carer Recognition Act 2010 are listed as key legislative context to the Victorian State Disability Plan 2017 – 2020.

**Recommendation:** The addition of a fifth key theme to state the principle that services and supports for people with disabilities should extend to individuals and families in care relationships with them. A fifth theme should also acknowledge many carers have disabilities themselves. The other four proposed Plan policy directions should be further developed to enhance a framework for carer partnership and inclusion. Likewise, Carers Victoria request the Victorian Government apply enhancement to recommendations arising from this consultation to include the needs of people in care relationships.

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## On the inclusion of family violence

Carers Victoria welcomes the inclusion of the issue of family violence within the context of the Victorian State Disability Plan 2017 – 2020. We acknowledge the high levels of violence experienced by people with disabilities in a range of circumstances. The development of the Plan is an excellent opportunity to address the needs of people accessing family violence services in Victoria.

We recommend carer experiences of family and intimate partner violence be considered, and their needs addressed in the design of any initiatives set up under the Plan to prevent and respond to these types of violence. We recommend carer needs be included within associated directives to create disability appropriate family violence services, and that people in care relationships are consulted during design processes.

Violence against carers can compromise their safety and the safety of people they care for. It can impact the quality of care they provide. Leaving a violent home becomes difficult when a carer is responsible for children or others who may demonstrate challenging behaviours and express severe anxieties; or have specific requirements such as the use of a wheelchair, hoist and other aids or; the administration of sophisticated medication regimens.

Family violence services may not always be aware of how to negotiate safety and emergency plans with people in care relationships. Competencies in this area need to be improved for the safety of all people with disabilities as well as carers.

As we have identified, a significantly high percentage of carers are women. In addition to this intimate partner violence is the leading preventable contributor to death, disability and illness in Victorian women aged 15 – 44 (VicHealth, 2010 p.10). Therefore, family violence is a critical issue for carer wellbeing. We are also cognisant of family violence within communities that have high rates of caring, such as LGBTI communities as discussed during the Victorian Royal Commission into Family Violence (Horsley, 2015; Aleksandrs & Phillips, 2015).

Recognition of the intersectional experience of coming from a diverse community, being in a care relationship, or having a disability is vital. Carers Victoria believes improved recognition of these intersections will better address and respond to the diverse contexts within which family and intimate partner violence can occur.

**Recommendation:** The application of cultural and carer competency indicators for use within service provision to improve outcomes for carers and key identified marginalised groups. This should be a core requirement for family and intimate partner violence service delivery designed for people with disabilities and carers. Carers Victoria requests that the Victorian Government resource the introduction of these indicators with regular professional development for sector staff.

**Recommendation:** Any directive or initiative to integrate the Victorian State Disability Plan 2017 – 2020 with a response to family violence include; carer consultation, carer needs identification, carer appropriate service development and carer data that can be collected and analysed via the Victorian Family Violence Index.

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## Active citizenship

Carers Victoria believes social exclusion needs to be addressed to make any real difference to the active citizenship of carers and people with a disability. We recognise the interconnectedness between family needs and a person/people needing support and assistance. In other words, good quality services and supports for a person with a disability can lead to a better quality of life for whole families.

Carers Victoria would like to see more carers and their families participating in the community. However, the mitigation of stressors and vulnerabilities that would enable this to occur is prevented due to barriers people in care relationships face trying to access a range of health, welfare and family support services.

As raised in our submission to the Inquiry into Social Inclusion for Victorians with a Disability, carer needs are not always directly related to the extent or nature of care they provide. Rather, needs arise due to a lack of support for their carer role. There is increasing evidence on carers' experiences of poorer health and wellbeing than the general population. This includes greater financial disadvantage, higher rates of disability or chronic illness; increased levels of anxiety and depression, as well as social isolation (Carers Victoria 2014).

Impacts of these circumstances can be barriers to the following:

- physical and built environments (due to a lack of access for the person/s they support or their own disability)
- leisure and physical recreation activities,
- opportunities to represent their communities and themselves, or
- opportunities to be an advocate on a variety of issues important to them.

The trickle-down effect is a direct impact on people with disabilities who require assistance to participate in a range of civic opportunities. For people with disabilities who are carers themselves, taking advantage of basic active citizenship opportunities can seem almost impossible as personal emphasis is placed on subsistence rather than personal expression.



Stigma and social exclusion related to disadvantage and discrimination is experienced by people in care relationships at greater levels than the broader community. This can affect whole families (biological families and families of choice), as well as individuals with a disability. People in care relationships who belong to marginalised groups can feel this more acutely. Such groups include LGBTI communities, CALD communities; or people at risk of homelessness and/or facing significant financial hardship.

## The Governments role supporting active citizenship

The Discussion Paper and Companion Document for the Victorian State Disability Plan 2017 – 2020 outlines possible initiatives that could be developed and implemented to aid the participation of people with disabilities. However, none of these initiatives are contextualised by the needs of people with disabilities in interdependent care relationships, or by those who may require family support. Nor does the Plan suggest *how* its list of initiatives could be implemented so carers also enjoy more civic participation.

Carers Victoria believes the issue of carer identification, recognition and inclusion are human rights issues that begin with the fundamental step of government, community and business acknowledging and recognising carers' rights and unique role. The Victorian Government must commit resources to undertake responsibilities outlined within the Disability Plan, which demonstrate commitment to the needs of people in care relationships and provide assurance they are on the community agenda.

The Victorian Parliamentary report on the Enquiry into Social Inclusion for People with a Disability featured submissions highlighting the importance of supporting carer participation and recognising carer relationships. Specifically, importance was placed on social inclusion and training programs (2014, p. 60) to cover community capacity building, disability awareness training and attitude changing initiatives.

Carers Victoria shares concerns raised in the Report about the future of such programs and agree the retention of these programs during the rollout of the NDIS is vital. The Victorian Government needs to clarify its responsibilities for inclusion work at a community and system level.

The report also made recommendations regarding existing policy tools designed to promote inclusion. For example, a recommendation was made the Victorian Government request the Victorian Auditor-General undertake an audit of the suitability, effectiveness, implementation, monitoring and improvement of disability action plans.

**Recommendation:** The Victorian Government undertake analysis of existing beneficial initiatives that have been conceptualised through recent disability plan development processes and inquiries, as well as key recommendations not yet implemented to explore how they fit within the themes of this Plan.

**Recommendation:** Outline a process within the Victorian State Disability Plan 2017 - 2020 to enact a series of recommendations from this consultation, which create disability friendly communities, thereby enabling broader civic participation.

**Recommendation:** The Victorian Government classifies people with significant informal caring roles and primary carers as a 'special needs' group across multiple policy platforms due to the range of barriers they face to participation in the community. In addition, the Victorian Government must identify 'carers with disabilities' as a special needs group within the Victorian State Disability Plan 2017 – 2020.

**Recommendation:** The Victorian Government includes an action within the Victorian State Disability Plan 2017 – 2020 to encourage community and business consultation with people in care relationships, their peak bodies and representatives on how to limit barriers to participation. For example, programs and services could embed evaluations and performance indicators that demonstrate people in care relationships are involved in activities or service design, and are provided greater choice, control and opportunities.

## **Community and business sector support of active citizenship for people with a disability and their carers**

Carers Victoria believes the community needs to understand and respond to the obligations and responsibilities under the following Acts: Victorian Equal Opportunity Act 2010; Carers Recognition Act 2012; Disability Discrimination Act 1992 and the Disability Act 2006.

These Acts apply to a range of business activities such as hiring people with disabilities, hiring carers, providing access to flexible work arrangements, ensuring non-discriminatory customer services and ensuring accessible physical environments. It also applies to appropriate planning, evaluation and review of services that include the experience of people with disabilities and those in care relationships.

As raised in the discussion paper, there are enormous benefits to an increase in representation of people with a range of disabilities and carers as staff, on boards, committees or reference groups and volunteer workforces. The broader community needs to be aware of discrimination which current legislation seeks to address, combat it and seek to minimise liability from breaches of legislation. It is up to everyone in the community to identify ways in which society can create opportunities for people in care relationships to participate in a full range of social, political, business and creative endeavors.

**Recommendation:** The Victorian Government must include an action within the Victorian State Disability Plan 2017 - 2020 to develop a community and business campaign (in consultation with disability, mental illness and carer groups) encouraging the audit, creation, monitoring, evaluation and review of disability and carer friendly policies, practices and inclusion.

**Recommendation:** The Victorian Government further resources and funds reasonable adjustments to create accessible infrastructure, organisations and services within local communities.

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## **Rights and equality**

Carers Victoria believes better inclusion of people with care responsibilities as both consumers and carers is required. Primary carers have a higher rate of disability (ABS, 2013), long-term health conditions (Edwards, 2008 p. 93) and significantly worse mental health (Edwards, 2008 p.65) than the general population.

Despite this, carers with disabilities are often not identified as consumers either by themselves or by service providers. Disability advocates, service providers and policy makers need to recognise care relationships. Carers with disabilities themselves need disability, health and mental health services which understand and support their care relationships, so they are able to carry on their caring roles in a manner not disadvantageous to them or the people they care for.

People with disabilities can experience scrutiny of their decision-making by human services and health professionals. A carer needs to know responsibilities agreed on between themselves and a person(s) they support are not compromised. Greater understanding of the Carer Recognition Act 2012 amongst disability advocacy organisations, as well as the human services and health workforce can contribute a layer of protection to care relationships from ableist views that people with disabilities are 'not fit to care'.

Carers Victoria would also like to see a system that is easier to navigate, with a reduction in the number of transactions made by people with a disability and people who support them. Any service planning, evaluation design or policy adjustments required to achieve this needs to include the perspectives of people in care relationships.

The perspectives of people supported by care relationships and carers can be combined to better identify critical higher order policy, funding and practice questions. Although the responsibility to deliver disability specific services will fall to the Federal government through implementation of the NDIS, the provision of adequate responses to the needs of carers by Victorian health and community services is vital.

The Equal Opportunity Act Section 6(e) identifies being a carer as an attribute by which it is illegal to discriminate against a person. Nonetheless, carers often feel their relationships are not recognised and respected by service providers, employers, or in health, justice, and education settings. These feelings can be more acute when carers belong to marginalised groups. This is because human rights as a carer, a person with a disability (or both), are not isolated from other lived experience.

For example, a lesbian caring for her partner with cancer may experience frustrations due to a lack of recognition by health providers that is exacerbated by an inability to be recognised as a legal spouse under current Federal law. Carers Victoria believes the impacts of direct, systemic and indirect discrimination need to be understood and addressed appropriately by service providers.

**Recommendation:** Carers Victoria believes the Victorian Government should identify ways to integrate the Victorian State Disability Plan 2017 – 2020 and its implementation, evaluation and data collection strategies with the Carers Recognition Act 2012.

**Recommendation:** Ensure any inclusion initiatives within the Victorian State Disability Plan 2017 – 2020 incorporating workforce development facilitate cultural competency and LGBTI appropriate service delivery.

**Recommendation:** The Victorian State Disability Plan 2017 - 2020 sets a framework for system reform that integrates service provision for people with a disability with services that support people in care relationships.

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## **Economic participation**

### **Carers are more likely than non-carers to have low household incomes.**

Sixty-five percent of primary carers have incomes in the lowest 40 percent of households compared with 36 percent of non-carers. Fifty-six percent of primary carers are reliant on a government pension or allowance as their main source of income. Only 37 percent of primary carers participate in the workforce. Consequently, 47 percent of primary carers have a gross household income in the two lowest quintile levels, compared to only 25 percent of non-carers (ABS, Survey of Disability Ageing and Carers, 2012).

Limited workforce participation and poor financial security can alter a person's quality of life dramatically. It can reduce leisure opportunities, as well as limit access to housing, healthcare, education, transport and other life necessities. This can result in social isolation and poorer wellbeing for people in care relationships.

Carers Victoria holds particular concern for families who are economically marginalised, sometimes across generations and over whole lifespans.

### **Young carers, barriers to education and life chances**

The Young Carers Research Project identified young carers aged under 18 are on average likely to be 12 or 13 years of age. Over two thirds of young primary carers are over 18 years of age (Carers Australia, 2002 p. 11). Over half of identified primary young carers care for a parent, mostly a mother, in a sole parent household. A young carer is most likely to assist a person with a physical disability or illness; however approximately a quarter of young carers assist a person with a mental illness (Carers Australia, 2002 p. 12).

Approximately 60 percent of young primary carers between 15-25 years are unemployed or not in the labour force compared to 38 percent of the general population in this age group (Carers Australia, 2002 p. 46). Only 4 percent of young primary carers aged 15-25 years are still at school, compared to 23 percent for the general population in this age group (Carers Australia, 2002, p. 41). These outcomes result in significantly higher risk of poor further education, economic and employment outcomes over the long term.

### **Reducing economic stress on carers and barriers to economic participation**

Carers can be key facilitators of participation in a range of life's domains for people with a disability; however this can depend heavily on a carer's economic stability and the ability to afford basics like transport, medication, communication tools and mobility aids. The interdependence and interrelatedness of the lives of people in care relationships is more constructively maintained by mechanisms that reduce barriers to work and improve financial stability and security.

Addressing employment and economic barriers for people in care relationships and taking significant steps to improve their quality of life would better acknowledge the contributions of unpaid carers to the Australian economy. In 2015, the annual cost of replacing unpaid care was estimated to be \$60.3 billion (Access Economics, 2015, p.6).

To enable higher rates of economic participation, circumstances need to occur that enable carers to balance employment with care responsibilities or re-enter employment if they are returning from an absence. They need time and resources to retrain or up-skill. To accept promotion opportunities, they need to be able to identify supports that allow more time to focus on career goals, and recuperate from more stressful workloads so they may continue to support other/s they are in care relationships with.

This requires exploration of how to increase flexibility in workplaces, schools and tertiary learning settings. There also needs to be a reduction in stigma associated with disabilities and caring roles. Considerable education is required in the general community, the business community and policy makers about the benefits of accommodating the needs of carers so their life chances are equal to others, enabling them to reach their full potential.

To benefit the lives of all people with disabilities the Victorian Government needs to be attentive and represent the most economically marginalised carers, particularly through income maintenance with attention to the Carer Payment and Disability Support Pension. We would like to see the Victorian Government advocate for the protection and increase of these working age payments.

## **Mental health and work participation: Trauma, mental illness and workplace injury**

Two issues are not explored in the Discussion Paper or Companion Document that Carers Victoria believes are worth consideration when discussing employment and economic opportunities.

These are:

1. the prevention of already disabling injuries and mental illness becoming worse; and
2. exploration of interventions that could lessen the impact of disabling injuries and chronic illness acquired during the course of employment.

For example, Carers Victoria supports many carers who assist others with psychological illness linked to severe or serious mental injury acquired while carrying out employment duties. Mental injury can result in a loss of earning capacity, personal distress and can put people at risk of a variety of comorbidities such as alcoholism as people seek to self medicate.

We believe improvements could be made to prevent long-term unemployment and minimise disadvantageous outcomes for people with mental injury trying to return to work. Recently there has been some focus from community, media and the Victorian Government on cases of Post Traumatic Stress Disorder (PTSD) acquired on the job within emergency services (Farnsworth 2016; Sanger 2015; & Willingham 2014). We also note commencement of a Victorian Ombudsman investigation into the management of workers compensation claims in Victoria. This investigation is the second ombudsmen inquiry into WorkSafe processes within a five year period.

Evidence has shown the significance of PTSD and the impact it can have on a person's thought processes, perception of reality, emotions, judgment and behaviour. Serious and severe PTSD injury can create significant strain on families and increase care responsibilities. Onus of living expenses and other financial commitments without prompt entitlements due to legitimate compensation claims creates further strain and prolongs the risk of poor recovery.

In some cases severe depression is associated with or triggered by PTSD and a person may experience suicidal ideation. This may result in their carer taking time off work in an effort to address risks to the other person's safety.

Carers Victoria welcomed very recent Victorian Government announcements regarding workplace training and pilot programs addressing traumatic experiences among fire fighters and paramedics. We believe the pilot program offering up to 24 one-on-one counselling sessions for fire fighters is a positive step to respond quicker to mental injury. We look forward to seeing an expansion of this program so it is available to staff in other high stress emergency professions.

However, we believe more can still be done. It is vital people who acquire severe mental injuries face minimal barriers to receiving prompt and effective assistance across a range of domains. People who care for those experiencing severe mental injuries also need to be supported. Their needs should be taken into consideration and WorkSafe systems should be supportive of the role they play navigating the pathways alongside the injured person.

**Recommendation:** The Victorian State Disability Plan 2017 - 2020 lists as an action the Victorian Government promptly adjust WorkSafe processes and procedures to minimise ongoing disadvantage to people who acquire a severe disabling mental injury during the course of their job; and to their families and carers wherever possible.

Examples of outcomes of such a review could be:

- The Victorian Government remove 'onus of proof' compensation requirements that rest upon people who acquire severe mental injury during the course of their employment within high stress sectors such as emergency services.
- The Victorian Government reviews current Worksafe systems to identify and address barriers that contribute to disadvantageous outcomes in recovery and future employment for people with mental injuries.

**Recommendation:** The Victorian Government develops a family and carer support framework overarching across services provided through the Worksafe system and under the jurisdiction of the Workplace Injury Rehabilitation and Compensation Act 2013.

**Recommendation:** The Victorian Government reviews and takes action on all recommendations by the Family and Community Development Committee outlined in chapter seven of their report on the 'Inquiry into Workforce Participation by People with a Mental Illness'. Carers Victoria believes these recommendations are a useful resource to identify preventative approaches in responding to lower workforce participation among people with mental illness.

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## A note on the importance of housing access

Carers Victoria agrees with the statement in the Victorian State Disability Plan 2017 - 2020 Companion Document; that access to affordable and suitable housing is fundamental for people with disabilities and people in care relationships with them. Without housing other important goals such as choice and control over support services, social participation, employment, health and wellbeing are not possible.

As raised earlier in this submission the majority of people with a disability live at home with family members or people they are in care relationships with. While this can be a positive choice, it can also be an economic necessity that undermines autonomy and choice for the person with a disability and their carer.

Housing policy for people with a disability must have a broader focus beyond primary homelessness and the housing needs of those with profound physical and/or sensory disabilities. Issues of access to housing for people with a disability are often reduced to those of *physical* access. However while this is an issue for some, economic and social barriers to housing access can be as significant and disabling for others.

During the Senate Economics References Committee Inquiry into Affordable Housing, Carers Victoria raised the issue of low levels of home ownership among caring families. This was particularly the case in metropolitan areas, where households require a dual income or considerable assets to afford property. Caring families also experienced difficulties in the rental market due to affordability issues, discrimination or a lack of appropriate modifications to properties.

Social housing offers some opportunities to people with disabilities failed by the market, however issues still remain, including:

- investment in social housing as a proportion of overall housing has been in steady decline
- eligibility for public housing does not include people with a disability currently receiving support in the family home
- additional policy levers are required at both supply and demand ends of the social housing sector. While housing associations are encouraged to grow their stock, there are no requirements to house people with a disability.
- continued reduction in public housing stock and a lack of access to community housing will mean social housing options for people with a disability are confined to public housing (Carers Victoria, 2014 p. 5).

## The Victorian State Disability Plan 2017 - 2020 and housing

The Companion Document referred to the need for people with a disability to *access* housing. This is a much weaker aim than *providing* housing or achieving housing *access targets*. A stronger aim would commit the Victorian State Disability Plan 2017 - 2020 to achieve real outcomes in collaboration with the Office of Housing and the Commonwealth Government.

While the Companion Document notes people with disabilities are more likely to live in public housing, there is no vision for increasing Government funded housing suitable to the diverse needs of people with disabilities.

Carers Victoria has advocated for the following concrete tasks and steps (Carers Victoria, 2012):

- changes to and investment in longitudinal data collection about people with a disability and their families
- Victorian population based planning for accommodation and support for people with a disability, including people with a psychosocial disability
- provision of housing assistance for people with a disability through setting clear targets and long term funding allocations
- working with the Commonwealth Government to reform Commonwealth Rent Assistance to address its inadequacies for those who live in high rental cost areas (i.e. capital cities)
- work to match eligibility settings between disability services and mainstream housing assistance. For example: the Disability Services Branch provides housing and support based on *disability* need, and the Office of Housing prioritises according to *housing* need. This issue is of great importance to the success of the NDIS as it creates inequity. It is also vulnerable to system/market distortions.

**Recommendation:** Carers Victoria supports recommendations outlined in 5.3 in the 'Enquiry into Social Inclusion of People with a Disability' report that;

- Government be more specific about its intentions to encourage the building industry, councils and social housing providers to incorporate the National Liveable Housing design guidelines; and
- create incentives to encourage the development of affordable housing that meets liveable housing design guidelines.

**Recommendation:** Carers Victoria supports recommendations raised by VCOSS referred to within the Companion Document to the Victorian State Disability Plan 2017 – 2020 that new dwellings be required to meet universal housing design principles (Victorian Government, 2016 p. 16 & VCOSS 2014, p. 12).

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# Making the most of the NDIS

## Psychosocial Disability should be included in the Victorian State Disability Plan 2017 - 2020

Developing clear policy directions around the needs of people with psychosocial disability within disability planning is vital. The current dynamic environment resulting from the transition of Victorian Government disability supports to the NDIS has created community and sector anxieties. Uncertainty around the financing of community mental health services has resulted in fears amongst some carers and consumers that they may not be eligible for NDIS supports.

This uncertainty is magnified by several factors:

- the number of packages available compared with the number of people who experience the consequences of severe mental illness
- the definition of 'disability' within the NDIS Act which is not clearly linked to recovery models used in the mental health sector or embraced by many people with mental illness and their carers
- the increased access and advocacy difficulties for many marginalised people created by having to navigate a new and changing system, and
- the reduction in community mental health services and staff that has occurred due to sector funding uncertainties.

The NDIS uses a definition of disability that refers to functioning as its guiding principle. This is in place of a disability type or diagnosis. The intention is to build an equitable service system based upon people's needs; however in practice, there are cultural and systemic barriers to using this approach consistently. In order to create consistency, and reaffirm the Victorian Government's commitments, the needs of people with psychosocial disability and mental illness must be incorporated within the Victorian State Disability Plan 2017 – 2020.

A more serious inclusion of people with a psychosocial disability in the State Disability Plan 2017 – 2020 would be a starting point:

- explicitly say in the Plan that this inclusion has occurred
- engage and include people with a psychosocial disability, people who care for and support them, and their representative bodies in the development of the plan
- consider reviewing the Disability Act 2006 to include people with a psychosocial disability
- acknowledge formal transition planning is required to examine implications for existing disability and non-clinical mental health sectors and services, and
- include the needs of people with a psychosocial disability who may be eligible for NDIS, as well as clinical services or services available through the health system.

Carers Victoria believes ongoing vigilance is required to prevent beliefs about people with a disability taking hold which promotes the idea that all people with a disability have similar needs, wants and aspirations. Difference should not be understood as being primarily about disability type. For example, it should not result in assumptions that all people with a

psychosocial disability have a common set of needs as a group that are different from, say, the needs of people with a physical or sensory disability.

Mental illness can result in long lasting impairment and reduced functioning i.e. disability. Up to 45 percent of Australians will experience a mental health disorder during their lifetime (ABS, 2009). Despite the inclusion of people with a psychosocial disability arising from mental illness in broad legislative and policy documents about disability, silos remain in practice. Stakeholders and governments fall short in service delivery due to historical, systemic and funding reasons. Existing silos are also likely to mean these groups are unaware of this Disability Plan and its relevance to them.

Carers Victoria believes service providers need to be actively aware of the ways in which mental illness and psychosocial disability can impact a person's life, as well as their families and carers. This would increase the likelihood of people being provided with adequate supports to access the NDIS.

## **An opportunity to reaffirm commitment to specialist services**

Alongside any disability supports available through the NDIS, many carers need access to specialist support in their own right, either because they belong to a particular carer cohort (e.g. young carers or older carers) or because they are struggling with issues that can be attributed to the caring role (e.g. leaving employment).

Carers Victoria believes a new State Disability Plan is an opportunity for the Victorian Government to clarify directions in service provision outside of, and complementary to the NDIS. Further consideration is required regarding how supports will be provided by the Victorian government in the context of the Commonwealth Government's new ***integrated carer support service*** model.

This requires particularly innovative thought regarding communities with few services specific to their needs and facing considerable barriers to accessing basic health or social care services.

In particular we encourage consideration of:

- carer specific services and supports based on a whole of family approach
- culturally appropriate engagement with and support for Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse backgrounds
- appropriate engagement with and support for LGBTI carers
- targeted assistance for carers in regional, rural and remote areas
- specialist support for carers transitioning from their carer role (where the person enters supported accommodation or dies)
- targeted assistance to carers wishing to enter or re-enter the workforce after their caring role has ceased or reduced
- access to flexible supports for carers who are employed or studying, and
- supports for young carers in the family and school environment.

It is important the range of health professionals who come into contact with carers on a regular basis are familiar with the concept of 'care relationships', understand the unique needs of carers and have the capacity to refer them appropriately. Establishing referral links and carer engagement strategies between carer support services and Primary Health Networks (PHNs) will be important.

## Input from people in care relationships

Carer consultants and carer peer support workers located at health service gateways also have a significant role to play informing health sector staff on carer needs, and raising awareness of service pathways for individual carers early in their caring journeys. These models have been utilised to great benefit in the mental health sector and could be extended across PHNs.

During the Parliamentary Inquiry into Social Inclusion for People with a Disability, the Family and Community Development Committee determined that by 2019 the Victorian Government is required to commence review of the Disability Act to ensure it aligns with the NDIS, reflecting the Victorian Government's future involvement in disability (see Recommendation 2.1, Inquiry into Social Inclusion for People with a Disability, p. 24). Carers Victoria believes thorough consultation with carers of people who are eligible and ineligible for the NDIS is required to strengthen the alignment of the new Disability Act with the NDIS.

## Individualised support and the market approach

Carers Victoria supports the intention of the NDIS to provide individualised, person centred care and empowerment to people with a disability and their families to exercise choice and control over their own lives. However, there will continue to be market distortions in disability support in the form of supply imbalances for some high needs groups, such as people with intellectual disability who demonstrate aggressive, self-injurious, anti-social or dangerous behaviours; and people with high medical needs, severe or profound disability and multiple impairments. 'Cherry picking' within the community care market has been demonstrated in relation to provider reluctance or refusal to provide services to the most vulnerable people.

**Recommendation:** The Victorian Government identifies ways to integrate the implementation of the Victorian State Disability Plan 2017 - 2020 with the 10 Year Mental Health Plan; and acknowledge directives within the Mental Health Act 2014 that may apply to the implementation of the Victorian State Disability Plan 2017 – 2020. Consistent language should also be used in the Plan and the NDIS Framework.

**Recommendation:** Develop a strategy to incorporate care relationships and carer awareness into the professional training of health, mental health, education and housing staff where carers can be identified.

**Recommendation:** The Plan includes a framework to ensure carers in identified special needs groups or families at risk of care relationship breakdown are eligible for specialist support, assistance and capacity building, as well as the planned integrated carer supports such as information, counselling, respite and peer support.

**Recommendation:** Initiatives within Victoria’s transition strategies to an NDIS encourage:

- the initiation of new and responsive individual or group behaviour support programs to fill gaps in the current services system through investment in infrastructure for community and program development, and
- capacity in the system to identify, establish, and support the development of new individual or group participation options for people with high needs.

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## Measuring the Victorian State Disability Plan 2017 – 2020: driving outcomes and accountability

Carers Victoria supports better integration of disability planning across State and local government and the development of an *outcomes framework*. This outcomes framework should embed identifiable and publicly communicated policy instruments and processes that provide clear measures and targets for greater accountability.

As part of a comprehensive outcomes framework Carers Victoria believes that progress reports on established measures and targets under any Plan outcomes should be reported publicly at major stages, as well as the end of each Plan. This includes reporting on key target and performance indicators for plans designed beneath broader frameworks that are aligned with key themes or focus areas.

In the context of likely transfer of current state disability services to the non-government sector as the NDIS rolls out, Carers Victoria supports similar accountability measures and public reporting requirements being extended beyond public sector agencies and statutory authorities. Carers Victoria believes a more rigorous measurement of outcomes of the Plan would assist to build the trust of the disability sector and people with disabilities, their families and carers.

Reporting on the success of the Plan should be based on an evaluation process designed in consultation with people with disabilities, their families and carers and the disability advocacy sector. Stakeholders involved in this process should include members of the Victorian Disability Advisory Council (VDAC) and local government disability advisory groups along with engagement with members of disability and carer support groups across Victoria.

Carers Victoria believes that the Office of the Disability Services Commissioner (DSC) and the Victorian Equal Opportunity and Human Rights Commission should also be engaged in the design of the outcomes framework and its evaluation. The Victorian Government should fund data collection and development within all funded health and human services to assist in counting consumers with care responsibilities, as well as consumers who identify themselves as being in care relationships.

In addition to the inclusion of data on carer status and being a party to a care relationship Carers Victoria supports Women with Disabilities Victoria’s call to ensure the Plan’s indicators have data disaggregated by gender, age, location, cultural background as well as LGBTI status.

Any goals reached under of the Victorian State Disability Plan 2017 - 2020 should be cross-checked with outcomes in a range of departmental areas to confirm broad success in the engagement, participation, health and wellbeing, economic outcomes, human rights and community access for people with disabilities and their carers. Results of reporting the outcomes framework should also be looked at alongside the aims goals and objectives of a Victorian Carer Strategy.

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