



Carers Victoria submission

National Arts and Disability Strategy Discussion Paper

An initiative of the Meeting of Cultural Ministers

DECEMBER 2018

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. 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.

This policy paper was prepared by Carers Victoria's Policy Team.

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Introduction

Carers Victoria welcomes the opportunity to comment on the National Arts and Disability Strategy Discussion Paper. Carers Victoria has addressed key themes in relation to families and carers of people with disabilities and made some suggestions of how the final Strategy might improve the inclusion of families and carers of people with a disability in the development and implementation of a renewed National Arts and Disability Strategy.

Recognising families, carers and supporting care relationships:

Carers Victoria notes the Discussion Paper does not refer to families and refers to carers and support workers interchangeably (page 4), however, Carers Victoria and other carers associations recommend a clearer distinction between these roles and terms. *Carer* is a legislated term under State and Commonwealth law¹ that is applied to a person who is in a care relationship with another person who has a disability, care needs from advanced aged, a mental illness, or an ongoing medical condition. These definitions specifically preclude persons who are providing care and support in a paid or voluntary capacity.

Unpaid care relationships between people providing care and people receiving care are multifaceted and dynamic. Carers can assist the person receiving care to monitor and ensure their wellbeing, navigate service systems, advocate for their rights and inclusion, as well as provide hands-on care.¹

There are 736,600 Victorian carers, representing 13% of Victoria's population:

- 55% are women and 45% are men
- 72% live in major cities, 23% live in regional areas and 5% live in rural Victoria
- 10% are young carers (<25 years), 68% are aged 25-64 years and 22% are aged 65+ years
- 58% participate in the workforce

Carer status and disability intersect

Thirty-one per cent of the 736,600 family carers in Victoria report living with a disability themselves; and 37% of the 239,100 primary carers in Victoria report living with a disability themselves.

¹ The two legislative mechanisms for this recognition are the Commonwealth Carer Recognition Act (2010) and Victorian Carers Recognition Act (2012).

Victoria's primary carers

There are 239,100 primary carers in Victoria, representing 4% of Victoria's population:

- 66% are women and 34% are men
- 37% report living with a disability themselves
- Their median gross income is \$455 per week compared with the national minimum wage of \$719 at 1 July 2018.
- 42% participate in the workforce
- 78% live with the person with whom they share a care relationship
- 41% care for their partner; 29% care for their child (including adult children); 21% care for their parent; and 9% care for another relative or friend
- 27% spend 40+ hours caring for the person with whom they share a care relationship
- 29% felt it was their family responsibility to take on the caring role; and 9% felt they had no other choice
- 58% had **not** received assistance from organised services in the last six months
- 28% didn't know the range of services available.
- 4% participated in a support group in the past three months
- 34% had not participated in any social or community activities without the recipient of care.

Source: Australian Bureau of Statistics (2015) Survey of Disability, Ageing and Carers, Australia: Victoria, Table 6.2 All persons, disability status, by age and living arrangements–2015.

Recognising inter-relatedness and interdependence

The Meeting of Cultural Ministers is likely to receive numerous submissions emphasising the importance of choice and control for people with a disability. Often this is assumed to be synonymous with independence. What frequently receives less attention is the fact that the majority of people with disability in Victoria live in the family

home, whether by choice or necessity. For Carers Victoria this fact is crucial in informing a discussion of a renewed National Arts and Disability Strategy.

There are two prominent sources of data which demonstrate most people with disability live in the family home, often beyond the time of their Australian peers who do not live with disability. Carers Victoria highlights these numbers to reinforce the importance of fully understanding the lived experience of all people living with disability or caring for a person with disability. Addressing the priorities raised in the Discussion Paper can only be effectively realised if the broader social milieu is taken into account.

The Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) 2015 shows the vast majority of people with disability live in households (defined as “private dwellings such as houses, flats, home units, townhouses and self-care components of retirement villages [in contrast to] cared-accommodation component covered residents of hospitals, nursing homes, hostels and other homes, who had been, or were expected to be, living there or in another health establishment for a period of three months or more”).²

LIVING ARRANGEMENTS Persons aged 15–64 years in Victoria	ALL WITH REPORTED DISABILITY	NO REPORTED DISABILITY	TOTAL
Living in households			
Alone	89.4	251.8	340.7
With others	476.5	3,122.0	3,596.5
<i>Total living in households</i>	<i>565.0</i>	<i>3,373.8</i>	<i>3,939.8</i>
Living in cared-accommodation	5.5	0.6	6.0 ³

The Australian Institute of Health and Welfare reporting for 2016-17 shows out of 330,984 service users, 50.4% (n= 147,936) live with family; 25% live alone; and 24.6% live with others. Importantly, the housing situation of 37,329 service users was not counted or stated.⁴

Legislative and policy reform context

Carers Victoria appreciates the intention of the National Arts and Disability Strategy Discussion Paper in developing a renewed National Arts and Disability Strategy; however, we believe it is important the regulatory, legislative and funding changes over the last nine years are fully understood, particularly their impact on people with disability, their families and carers.

² <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4430.0Explanatory+Notes12015>; accessed 21 November 2018.

³ Australian Bureau of Statistics (2015) Survey of Disability, Ageing and Carers, Australia: Victoria, Table 6.2 All persons, disability status, by age and living arrangements–2015, Relative Standard Error of estimate

⁴ Australian Institute of Health and Welfare (June 2018) Bulletin 144: *Disability Support services: Services provided under the National Disability Agreement 2016-17*, p. 17.

It should also be noted Australia's response to the United Nations Convention on the Rights of Peoples with Disabilities and implementation at a State/Territory and Commonwealth levels has been slow. Meaningful law reform in areas of guardianship have not been legislated. The introduction of the National Disability Insurance Scheme (NDIS) – while offering many people funding for services they had not previously been eligible for – has been widely recognised by Governments and advocacy agencies as problematically implemented.^{5, 6}

A major factor in the problematic implementation of the NDIS is the unevenly developed access to mainstream services such as education, health, transport and justice. Like the NDIS, the National Arts and Disability Strategy is not responsible for these other systems, particularly when there are State or Territory jurisdictional priorities; however, without appropriate regard for the inter-connectedness of these systems, arts engagement for people with disability, their families and carers will continue to be ad hoc and subject to lotteries of personal circumstance.

Furthermore, while the National Disability Insurance Agency (NDIA) reports quarterly regarding the number of participants in the National Disability Insurance Scheme (NDIS), the disability of participants, functional level etc, it is important for the Department of Communications and Arts to note the Agency does not collect future demand data or 'aspirational' data. In other words, planning meetings tend to be focused on day-to-day living situations rather than having a future-planning orientation. Therefore, it is unlikely meaningful data collection about unmet demand for connecting to the Arts is likely to be sourced about NDIS participants until this approach changes.

With the introduction of the NDIS and reforms to carer support services, funding for families and carers to access and engage in the Arts has diminished. Funding for the following carer-specific programs has been earmarked to transition to the NDIS and will be terminated by the end of 2019:

- Respite support for carers of young people with severe or profound disability
- Young carers respite and information services
- Mental health respite: carer support, and
- Better Start.

Any family or carer wishing to access carer-specific support is unlikely to be eligible if the person(s) for whom they care is eligible or a participant of the NDIS. This is based on the presumption the NDIS will provide a 'respite-effect' for families and carers; however, as Carers Victoria and other carer associations have argued, family and carer inclusion and recognition in NDIS planning and funded supports is inconsistently applied.⁷

⁵ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs*, Study Report, Canberra.

⁶ Joint Standing Committee on the National Disability Insurance Scheme (September 2018) Market readiness for provision of services under the NDIS

⁷ Ibid.

Recommendations to address barriers to access

As the Discussion Paper notes, it is well recognised having a disability in Australia can lead to detrimental outcomes in many domains of life including education, health and employment. Yet there is a growing evidence base demonstrating disability also impacts on the individual's family⁸ and/or informal networks. Unsupported and/or under-resourced caring roles can often have significant cost for an individual or family's mental and physical health, financial wellbeing and security.

Care responsibilities can commonly have an adverse effect on the emotional and physical wellbeing of carers who experience greater exhaustion, stress, anxiety depression, injury and physical ill health than those not in a caring role.^{9, 10}

BARRIERS TO CONNECTING

The Discussion Paper highlights barriers to connecting continue to exist for people with disability. Carers Victoria believes the continued existence of these barriers will not be fully addressed until the broader social and economic exclusion of people with disability, *their families and carers* - where costs associated with attending cultural events in Australia from ticket prices, costs associated with public or specialist disability transport, parking (or lack of) and other costs entailed – is fully understood in relation to increased costs associated with living with disability, minimum wages, casual and insecure employment or Commonwealth income support payments well below Australian minimum wage levels.

These factors impact on the way people with disability, families and carers engage in the arts across the spectrum identified in the Discussion Paper.

Carers Victoria has consistently advocated for increased recognition of carers in Government policy (Federal and State) as people with needs in their own right, as well as acknowledging the outcomes for people with a disability are inextricably linked with people who are in care relationships with them.

People in care relationships have different needs to support their access and engagement with the Arts. For carers, support includes but is not limited to the provision of adequate respite – or substitute care so they may attend activities outside the home. Adequate respite is high quality and allows sufficient time for the carer to prepare and travel between the activity and home.

Carers Victoria recommends the renewed National Arts and Disability Strategy more explicitly emphasises the diversity of carers and indeed the ways families and carers engage in the Arts, as creative and cultural professionals, through participation in

⁸ When using the word 'family', Carers Victoria recognises the diversity of family structures and may reflect that 'family of choice' may replace biological family as the primary source of support.

⁹ Australian Bureau of Statistics (2013) 2012 Survey of Disability, Ageing and Carers Australia, Cat. No. 4430.0

¹⁰ Carers NSW, 2012, Biennial Carer Survey

recreational creative activities and as audience members. As the statistics from the SDAC highlighted in Table 1 attest, this can reflect carers' life-stages and opportunities to participate independently or in conjunction with the person with whom they are in a care relationship.

Following on, Carers Victoria recommends the renewed National Arts and Disability Strategy aligns itself more explicitly to the Policy Direction 1 of the *National Disability Strategy 2010-2020*: Increased participation of people with disability, their families and carers in the social, cultural, religious, recreational and sporting life of the community.

Table 1: Carer engagement in arts activities

	Age group of primary carer					Average weekly hours spent caring			Total
	PROPORTION OF PERSONS SURVEYED (%)					1-19 hours	20-39 hours	40 hours or more	
	15-34 years	35-54 years	55-64 years	65 years and over	65 years and over				
Activities participated in a home in last 3 months									
Art or craftwork or practical hobby group	16.5	15.2	12.9	10.2	16.5	13.6	10.9	13.4	
Art or craftwork or practical hobby group without the recipient of care	11.6	11.1	10.6	6.9	14.2	9.3	6.4	10.1	
Other special interest group activities	6.0	5.7	6.4	5.0	8.0	5.2	4.0	5.7	
Other special interest group activities without the recipient of care	3.5	3.3	5.0	3.5	5.4	3.4	2.0	3.8	
Did not participate in any of these activities	1.7	1.3	2.8	1.0	1.5	0.0	3.2	1.9	
Did not participate in any of these activities without the recipient of care	18.5	21.5	20.5	31.7	13.7	19.2	36.9	23.7	
Activities participated in away from home in last 3 months									
Performing arts group activity	4.0	10.3	9.1	6.9	11.3	8.2	6.0	8.5	
Performing arts group activity without the recipient of care	4.1	7.3	5.1	4.8	8.4	5.8	3.5	5.9	
Art or craft or practical hobby group activities	9.4	9.3	8.7	5.9	11.3	7.2	6.6	8.4	
Art or craft or practical hobby group activities without the recipient of care	5.5	7.7	7.4	5.0	10.0	5.0	3.5	6.6	
Other recreational or special interest group activities	11.7	11.2	11.7	12.5	13.9	12.1	8.6	11.5	
Other recreational or special interest group activities without the recipient of care	7.0	8.7	8.6	9.5	11.2	8.7	6.6	8.8	
Support groups	1.0	3.4	2.8	2.0	1.9	3.5	3.2	2.8	
Support groups without the recipient of care	1.4	2.4	2.9	0.7	0.8	3.8	1.8	1.8	
Other activity not specified elsewhere	4.0	2.0	1.4	2.7	2.5	1.9	2.3	2.3	
Activities participated in away from home in last 12 months									
Visited a public library	28.6	38.2	29.3	29.6	35.5	34.3	29.7	32.6	
Visited a public library without the recipient of care	19.4	25.9	24.0	20.4	28.9	23.7	16.4	23.0	
Visited a museum or art gallery	23.0	24.5	24.2	15.3	29.2	18.9	14.9	21.7	
Visited a museum or art gallery without the recipient of care	13.5	14.9	17.6	7.9	22.1	8.8	6.2	13.4	
Attended a movie, concert, theatre or other performing arts event	64.2	59.9	51.1	42.4	64.3	50.5	44.1	53.5	
Attended a movie, concert, theatre or other performing arts event without the recipient of care	43.9	44.5	37.0	22.9	46.2	36.6	27.1	36.7	
Visited a botanic garden, zoo or aquarium	33.8	32.9	23.2	15.0	29.9	27.3	21.7	25.9	
Visited a botanic garden, zoo or aquarium without the recipient of care	15.2	15.4	15.2	7.0	19.7	12.7	6.1	13.1	

Please note the statistics in this table are from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (2015); numbers for carers attendance at cultural or arts events were taken from Table 46.3 Primary carers, living in households, social and community participation, by age of primary carer and average hours spent caring each week-2015, proportion of persons. Numbers for carers' attendance at cultural or arts events without the recipient of care were taken from Table 47.3 Primary carers, living in households, social and community participation without the recipient of care, by age of primary carer and average hours spent caring each week-2015, proportion of persons.