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Christine Mulholland Senior Policy Officer Office for Disability

Re: Draft Department of Health and Human Services Disability action plan 2018-2020.

# **Background information**

Carers Victoria is the state-wide peak organisation representing people who provide unpaid care. There are approximately 736,600 family and friend carers across Victoria, representing 13 per cent of the State's population. People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. Under Victorian legislation, a carer is defined as a person who is in a care relationship with another person who has a disability, care needs from advanced age, a mental illness, or an ongoing medical condition.

# Carer status and lived experience of disability intersect

31 per cent or 228,346 of all carers in Victoria report living with a disability themselves.<sup>i</sup>

In 2016-17, approximately 67 per cent of Australian disability service users had the support of a carer; "...83 per cent reported that their informal carer helps with one or more activities of daily living (self-care, mobility or communication).<sup>ii</sup> In Victoria there are 5900 primary carers over the age of 65 providing the most support and assistance to adult children with a severe or profound level of disability.<sup>iii</sup> Just over 7,000 Victorians receiving support from a carer continue to live in the same household as their parent over 65 and only 900 live outside the family home.<sup>iv</sup>

# Overarching comments on the draft Disability action plan 2018-2020

Carers Victoria has consistently advocated for increased recognition of carers in Victorian Government policy, as people with needs in their own right and in acknowledgement the needs of and outcomes for people with a disability are inextricably linked with those of the people in care relationships with them.

However, the draft Disability action plan does not refer to important policy or legislation that support people with disability, their families and carers. In Victoria the legislative basis for this is the Carers Recognition Act (2012) which is intended to support care relationships by having each person in the care relationship and the care relationship itself respected and honoured, and if appropriate, have the views of each person in the care relationship considered in the assessment, planning, delivery, management and review of services affecting each individual and the care relationship. Carers Victoria is pleased the Department of Health and Human Services reports on its compliance with the Carers Recognition Act in its Annual Report.

The National Disability Agreement reflects the commitment of State and Territory Governments "to [develop] strategies that focus on improving outcomes for carers of people with disability". As a result of these omissions, the draft Disability action plan does not effectively address the needs of people with disability, their families and carers. This reflects a rather ad hoc Government commitment including the absence of a framework for measuring the impact of any strategies on all people in care relationships.

Carers Victoria makes the following recommendations in response to the draft Disability action plan 2018-2020.

# Legislative and policy context

# **Recommendation One**

Add the National Disability Agreement to the Legislative and policy context for the department's Disability action plan (page 10). The National Disability Agreement, introduced by the Council of Australian Governments in 2009, is a high-level agreement between the Australian and state and territory governments for the provision of disability services for people with disability. It features clear roles and responsibilities for each level of government and joins these efforts together though nationally agreed objectives and outcomes for people with disability, their families and carers. One of the joint reform priorities is a focus on Enhancing Family and Carer Capacity.

### **Recommendation Two**

Add the Victorian Carers Recognition Act (2012) to the Legislative and policy context for the Department's Disability action plan (page 10).

# An action plan for all people with disability

# **Recommendation Three**

Ensure a de-differentiated disability policy. Not all disabilities manifest in the same way and people with the same condition have different functional capacities. Without adequate reference to the impact of specific disabilities and/or conditions, the draft Disability action plan 2018-2020 risks oversimplification of diverse life circumstances.

#### **Recommendation Four**

Make reference to people with disability over the age of 65 who have specific needs intersecting with age and disability, gender and sexual identity, cultural background and locality.

# Children with disability

# **Recommendation Five**

State DHHS's intention to work proactively with children with disability, their families and carers to reduce the incidence of family crisis resulting from unmet demand for responsive and family-focused disability services irrespective of the child's eligibility for the NDIS.

### **Recommendation Six**

Implement the recommendations made in the Victorian Equal Opportunity and Human Rights Commission 2012 report <u>Desperate measures</u>: The relinquishment of children with disability into state care in Victoria.

### Adults with disability living with ageing parents

# **Recommendation Seven**

Make reference to adults with disability supported by parents who are aged over 65 years and whose life-long caring commitment has had a significant impact on their physical and emotional wellbeing.

# **Recommendation Eight**

Provide specific performance indicators of partnership between DHHS, the NDIA and other key community agencies to support the transition of adults with disability living with ageing parents into appropriate accommodation settings, well supported by their remaining family (if any), community and formal supports.

Carers Victoria acknowledges this is only a brief response to comprehensive document. We would welcome the opportunity to discuss these points and others with you to ensure the final Disability action plan 2018-2020 enhances the wellbeing of all people with disability and the people with whom they share a care relationship.

If you wish to discuss any of the points we have raised, please contact disability and housing Policy Advisor Margaret Boulos in the first instance.

Yours sincerely

Scott Walker CEO

<sup>&</sup>lt;sup>i</sup> ABS, (2015), Disability, Ageing and Carers, Australia, Victoria, Catalogue # 4430.0

<sup>&</sup>lt;sup>ii</sup> Australian Institute of Health and Welfare 2018. Disability support services: services provided under the National Disability Agreement 2016-17. Bulletin no. 144. Cat. No. AUS 223. Canberra: AIHW.

<sup>&</sup>lt;sup>iii</sup> Table 38.1 Primary carers, relationship of carer to main recipient of care, by age and sex of primary carers–2015, estimate.

<sup>&</sup>lt;sup>iv</sup> Table 39.1 Primary carers, whether main recipient lives in same household, by relationship of carer to main recipient of care, by age of primary carer–2015, estimate.