

Disability legislative reform 2022 - Recognising and embedding the role of unpaid carers

Carers Victoria is pleased that the Disability Inclusion Bill Exposure Draft recognises the role of carers, with clause m of the Inclusion Principles stating that

"relationships between people with disability and their families, carers and other significant people are a crucial part of the lives of people with disability and should be preserved".

This is a positive development, and we thank all involved for taking this important step in recognising that both people living with disability and the people who support and/or care for them have a valid role to play in shaping the Victoria disability system.

Combining these different perspectives and experiences will ensure the Disability Inclusion Act remains **contemporary and responsive to the needs and preferences of all in years to come**.

We are however keen to see that objective given practical effect through legislation and/or supporting regulations.

Currently, carers perspectives are often not present despite the critical role they play in supporting people with disability across the state. New disability inclusion legislation offers a rare opportunity to remedy this.¹

Legislating the inclusion and representation of carers will reflect the lived experience of people with disability, allowing their insights and expertise to also inform and shape the plans which impact their lives.

This can be achieved without compromising the autonomy or influence of people with disability. Carers respect the right of people with disability to exercise their autonomy, and can play a central role in supporting people with disability to do so by providing wide-ranging assistance to foster that person's independence and dignity.

In saying this, we recognise that there are times where the perspectives of people with disabilities and their carers/supporters may not align. We acknowledge that this may be a circumstance to be navigated on occasion; in our experience:

- this is the exception rather than the rule;
- by selecting the right candidate/s, this could be managed (consideration could be given to a candidate who is both a person with a disability and a carer, for example), and;
- the most successful advisory functions are those where a diversity of opinions are invited and shared.

¹ There are estimated to be of the order of 300,000 Victorians caring for a person with disability and with the size of Victoria's unpaid care population growing rapidly this number will increase further. It is also noted that unpaid carers typically experience higher rates of disability than the general population, with an estimated 37% of primary carers also living with a disability themselves - twice the rate of non-carers.

With all of the above as context, Carers Victoria is requesting that future legislation:

- be amended to create a clear and documented role for carers in relation to shaping the State Disability Action Plan,
- include carers as one of the groups to be included in co-design processes,
- designate a place on the Disability Advisory Council for a person with living or lived experience of caring for a person with a disability, and
- incorporate a definition of carers, as defined in the Victorian Carer Recognition Act.

The new disability inclusion legislation offers a **once in a generation opportunity to set a new and expansion vision of disability inclusion in this state, and in doing so to recognise the importance of care relationships across the system.**

Carers Victoria thanks government for the opportunity to comment, and looks forward to the opportunity to discuss these proposals further.

How could these changes be achieved through amendments to legislation?

To ensure carer perspectives become an integral part of co-design and planning processes, Carers Victoria proposes that the following changes be made to the current legislative proposal:

Clause a of subsection 12 (Part 4) and clause 4 of subsection 15 of the Bill in relation to the process for development of the State Disability Plan and those of defined entities be amended to include people with lived experience of caring for people with disability and establish goals and priorities for carers,

Clause 2 of subsection 50 (Part 7) of the Bill regarding Victorian Disability Advisory Council be amended such that at least 1 position is reserved for a person with lived experience of caring for a person with disability,

Clause f of subsection 7 (Part 1) of the Bill's Objectives which sets out the definition of co-design be amended to make reference to carers.

The definitions section of the Bill be amended to note that carers means the definition contained in the Carer Recognition Act 2012.

For further information please contact:

Dr Margaret Boulos

Senior Policy and Research Advisor

Carers Victoria

T: 1800 514 845

M: 0407 327 297

E: margaret.boulos@carersvictoria.org.au

www.carersvictoria.org.au