



**ILC Commissioning Framework
Consultation Draft**

Carers Victoria

Submission April 2016

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.

This submission was prepared by Carers Victoria's Policy Team.

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Introduction

Carers Victoria welcomes the opportunity to provide a submission in response to the draft ILC Commissioning Framework. While the NDIA provided a submission form and list of questions, Carers Victoria has chosen to respond to the ILC Commissioning Framework using our submission template as the response form is difficult to use and limits areas for response, in contradiction to the principles of co-design.

Carers Victoria has been, and will remain to be, involved in lobbying for improved services and support for people with disability, their families and carers¹. We have been active in the development of the NDIS and provide information and capacity building for carers for the NDIS transition and rollout in Victoria.

Carers Victoria's position is that services and supports for carers are integral for sustaining the enormous amount of informal care and support provided by carers of people with disability. According to the Productivity Commission², the vast majority of people with disability who indicate that their core needs are met are having their needs met through informal support. If care provided by family carers cannot be sustained, there will be increased demand on the NDIS.

Delivering the NDIS and realising the potential gains in wellbeing for people with disability and their carers requires services and support for carers separate to the person they are caring for. Carers Victoria (along with our other carer associations) remains deeply concerned about the lack of clarity regarding where and how carer supports will be funded and delivered.

Position statement on behalf of the National Network of Carers' Associations

As a member of the National Network of Carers' Associations, Carers Victoria refers the NDIA to the position statement in the Carers Australia submission which outlines the position of the National Network.

In addition, Carers Victoria would like to make additional comments and recommendations regarding four of the nine outcomes, the move to outcomes based performance measures and the intention to grow social capital across the sector.

¹ The terms 'carers', 'family carers' and 'caring family/ies' used in this submission includes the diverse range of people in care relationships, including carers and people receiving care in same-sex families, 'families of choice', friends and others who provide unpaid care.

² Productivity Commission (2011) *Disability Care and Support*, Productivity Commission, Canberra.

The Nine Outcomes

The inclusion of outcomes is supported by Carers Victoria, particularly the inclusion of an outcome focused on carers. Carers Victoria recommends the proposed outcomes be refined so they are clear, achievable, measurable, and represent the interests of people with disability, their families and carers.

There are four outcomes of the nine outlined in the consultation draft that Carers Victoria wishes to provide specific commentary:

1. People with disability have capacity to exercise choice and control in pursuit of goals

Carers Victoria supports this outcome and believes all people have capacity to make decisions, while acknowledging everyone, including people with disability, will seek and require support to make decisions. Carers who are caring for people with disability are providing decision-making support so that choice and control can be exercised. Investing to build the capacity of families, carers, service providers, legal professionals and other parties to provide decision making support to people with disability in exercising choice and control is fundamental to achieving this outcome. This would fall outside of the role of the LACs and is required for all people with disability, including scheme participants.

Carers Victoria recommends capacity building to provide decision making support for people with disability be included as a priority investment area, either through priority area 1 (specialist or expert delivery of activities) or priority area 2 (cohort focused delivery). As such, there is an opportunity for people with disability to be involved in the development and delivery of capacity building for people providing decision making support, thereby including priority investment area 5 (delivery by people with disability for people with disability).

2. Independence and social/economic participation of all is promoted

This outcome does not specify who 'of all' refers to. It appears from the diagram and pictorials that this outcome refers to individuals, but it is not clear if this is scheme participants, all people with disability, and/or their families and carers. An essential component for the sustainability of the NDIS, as specified in the Productivity Commission report, is for carers to be able to enter or re-enter the workforce. In addition, and when considering increasing carer independence and participation, addressing the isolation and stress carers can experience will assist through supporting social participation of carers. This is a key factor in sustaining the care relationship.

Carers Victoria strongly supports the social and economic participation component of this outcome being clarified to include people with disability (scheme participants and people with disability who are not eligible for individual support packages), their families and carers.

3. Informal support and care arrangements are upheld and nurtured

This outcome assumes the informal support and care arrangements in place are sufficient and sustainable. There is no mention in this (or other) outcomes about how services will be provided to those who are providing this informal support and care arrangements. It is also not clear what 'upheld and nurtured' would mean in a practical sense for carers.

Carers Victoria recommends this be refined so the outcome is more definitive and measurable.

4. Participants can access unfunded supports and individual funding is provided at the optimal time

The language for this outcome is unclear, as unfunded supports could be informal supports and therefore may overlap with the previous outcome. This outcome does not define whether 'participants' means only those who are NDIS participants (receiving individual funding), or whether this outcome is intended to include ILC participants, who may also include families and carers.

Carers Victoria recommends clarifying these sections of this outcome.

Outcome based performance measurement

Carers Victoria is supportive of outcomes-based performance measurement. However, this is a significant issue if organisations such as Carers Victoria deliver services and supports for carers but are expected to demonstrate the outcomes of such services for scheme participants and people with disability receiving ILC supports. Carers Victoria currently collects data about the care relationship, including the person receiving care, as part of the carer assessment. However, this information is recorded to assist with designing the most appropriate supports for the carer in their caring role.

Such a change in data collection and reporting would result in significant costs for the organisation to redesign data capture and reporting systems, along with associated forms, processes and resulting administration. This approach also does not align with our support for separate and distinct carer services and supports that meet the needs of carers, regardless of the age or condition of the person they care for.

Growing social capital across the sector

While the Commissioning Framework describes opportunities for co-design, we question whether this would be better labelled as opportunities for consultation. There are a number of fixed and pre-determined elements of the Commissioning Framework that are being explained through the Commissioning Framework, with feedback opportunities limited to answering questions on areas where the NDIA is seeking feedback (such as the structure of the feedback document). True co-design reflects the experience of participants and shares the decision making.

Building social capital through the development of relationships between organisations and others in the community requires adequate funding to employ people with the necessary skills and experience. The Commissioning Framework is clear that advocacy (both systemic and individual) will be outside of the remit of the ILC, as is funding for organisations to provide policy advice. There are important social capital benefits when representative organisations can join together for policy development and advocacy, along with skill development and training of their members so they can participate in policy processes. It is unfair and unreasonable to expect this work be undertaken on a voluntary basis, placing the financial and time burden for participation on those who are most at risk of being unable to afford to do so.