



**Carers Victoria submission  
A Framework for Information, Linkages and Capacity Building –  
Discussion Paper released February 2015**

**Carers Victoria**

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### **About Carers Victoria**

Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for a person with a disability, mental illness, chronic health issue or someone with an age-related condition. The people being cared for could be a parent, child, spouse, grandparent or a friend.

Carers Victoria is a member of the National Network of Carers Associations, as well as 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 primarily consist of 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.

Carers Victoria welcomes the opportunity to provide input to the NDIA regarding the 'Framework for Information, Linkages and Capacity Building'.

The paper presents the policy parameters for Information, Linkages and Capacity Building (ILC) and this framework will provide guidance to the NDIA in developing a transition and implementation strategy. The comments from Carers Victoria relate to these policy parameters and are presented in the context that rollout and transition plans for the NDIS in Victoria that are not yet publicly available. In addition, the Department of Social Services (DSS) is currently designing an Integrated Carer Support Model for all carers regardless of the age and condition of the person they are caring for. Carers Victoria is therefore unable to comment about the integration of these various programmes and plans in conjunction with the design of the ILC without further detail being available.

## **Background – family carers and the role of Carers Victoria**

Carers<sup>1</sup> provide unpaid care and support to a family member or friend needing assistance with a disability, mental illness, chronic health condition or age-related frailty. Carers come from all walks of life, across all age groups and all cultures. Not all carers identify themselves as carers, and may instead identify themselves in terms of their family and friend relationships.

There are an estimated 773,400 informal carers in Victoria, which is 13.6% of the Victorian population. Of these, 217,800 (3.8% of the Victorian population) are primary carers, defined as providing the majority of ongoing care to the person requiring assistance<sup>2</sup>.

Carers Victoria supports caring families through information, online and face to face training and education programs, respite support, counselling and systemic advocacy. In 2013-14 Carers Victoria had 28,545 interactions with carers through our carer advisory line, counselling and other support services.

## **Carers Victoria comments**

### **1. What are the most important elements of ILC?**

Each element of the ILC has a specific purpose and will be equally important within the ILC design as a holistic approach. A well designed ILC framework with elements that provide the right supports at the right time for people with disability will have flow on benefits to their families and carers. This combination will support the care relationship and assist to build resilience.

An important element of the ILC is that ILC services will be accessible to people with disability eligible for an NDIS individually funded package (IFP, or Tier 3). Following on from this principle, it is vital that families and carers of people with disability who are eligible to receive an IFP are also able to access ILC services and supports.

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<sup>1</sup> 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.

<sup>2</sup> Australian Bureau of Statistics (2013) *2012 Survey of Disability, Ageing and Carers*, Cat. No. 4430.0.

From the carer perspective, the most important elements appear to be:

- *Stream four: Individual capacity building* that provides examples of programmes and counselling for carers as supports that will be funded under this stream. However the accessibility to these programmes and their relationship to the proposed Integrated Carer Support Model being designed by the DSS are unclear.
- *Stream one: Information, Linkages and Referrals* that provides examples of the types of information that may be sought by carers. Carers Victoria supports the development of, and linkages to, information that will assist them to navigate service support systems, as well as information to assist them in their caring role. Carers Victoria believes that information for carers can be provided through a variety of mechanisms, including online, potentially through a specialised carer gateway and an online portal as part of an integrated carer support model.
- *Stream three: Community awareness and capacity building* that provides examples of public campaigns, networks, training and consultation. This stream highlights the opportunity to gain input from carers in the design and delivery of community awareness and capacity building activities, including:
  - Product and technology design;
  - community activity design;
  - training of service providers; and
  - delivery of other goods and services.

## **2. What is missing from the ILC Policy Framework?**

### **a. Connection to Integrated Carer Support Model**

As the Integrated Carer Support Model is still being designed by DSS, it is not clear how carers of people with disability (including those who are eligible for an IFP as well as those eligible only for ILC) will access carer specific information and support services.

### **b. Systemic advocacy**

The ILC paper references initiatives under *Stream three: Community awareness and capacity building* to consult with or incorporate the view of people with disability, their families and carers in the provision of community activities and other goods and services. However, there is no reference or provision for systemic advocacy by organisations who represent people with disability, their families and carers. While the intention to consult is commendable, it needs to be complemented by resourcing for systemic advocacy to allow for representation in ways that go beyond formal consultation processes.

### **c. Quality monitoring and complaints framework**

It is not clear from the paper as to whether there will be quality monitoring and complaints framework in place so that people with disability, their families and carers can make complaints and seek resolution of these complaints for services they receive under ILC, including mainstream services. While there may be existing complaints

mechanisms in place for mainstream services, these may require additional support and capacity building to ensure they are available and responsive to the needs of people with disability, families and carers. An important principle of any complaints framework that applies to people in care relationships is for carers to be able to complain about their own treatment by the service provider, even when the direct service user is the person with disability. Under the same principle, a person with disability should be able to complain about their treatment as part of services provided to their carer.

#### **d. Definitions of one-off, low level or episodic support**

*Stream four: Individual capacity building* discusses the provisions of supports as being one-off, low level or episodic supports. However, Carers Victoria believes that carer support services should be available and responsive to carers as their needs change and evolve throughout their caring journey, particularly at key life course transitions such as when their child with a disability becomes an adult.

Some examples from Carers Victoria services include support for carers through phone support via our information and access line. Carers may have their needs met through a single phone call, or they may call at various times as their circumstances change and evolve. These services may be one-off episodes of support but are required at various stages by the carer during the carer journey. Another example is carers who access counselling services, who may require a series of counselling sessions to meet all their needs for emotional support, skill building and future planning. While these supports could be defined as one-off, low level or episodic, they should be available to carers as and when they need them.

#### **4. How will we know the ILC streams are meeting their objectives/vision?**

Without some form of reporting framework that reports publicly available information, it will not be clear whether the ILC streams are meeting their objectives/vision. There is also the potential that people with disability, their families and carers will fall through the gaps if:

- a) the ILC does not work as an integrated whole; and
- b) additional supports are not maintained and/or put in place while the capacity of mainstream services are being developed and enhanced.

Any monitoring and reporting framework will need to measure the effectiveness, efficiency and equity services (specific and mainstream) being delivered through the ILC streams, including their quality, accessibility and appropriateness. A focus on reporting outcomes will assist to determine whether the ILC streams are meeting their objectives.

#### **5. What would be the implementation challenges?**

There are a range of implementation challenges arising from this framework. The most prominent of these is that withdrawal of specific support services for people with disability, their families and carers cannot commence until mainstream services have the capacity to adequately meet the needs of people with disability, their families and carers.

Funding supports that are not directly tied to an individual leads to a service system that requires the person with disability, their families and carers to navigate and negotiate these services. Carers Victoria believes assistance with skill development will be required so that people with disability, their families and carers can successfully perform this role within this framework.

Another implementation challenge is how to balance national consistency in service outcomes while preserving the ability of services to provide local responses to local needs.

## **6. Which aspects of a person's life do you think ILC could have the greatest impact on?**

If the ILC framework is developed and implemented so that the streams operate as a seamless whole, there will be flow on benefits for families and carers of people with disability. Some life course transitions such as from childhood to adulthood are predictable and can be supported with targeted planning and provision of practical and emotional support for individuals and families, whilst other life events such as relationship breakdown, unemployment and ill health may be less predictable and require prompt and highly responsive interventions. If people with disability and their families and carers can access the flexible and responsive supports they need at the times they need them then there can be avoidance of the escalation of situations to points of crisis when intensive intervention is required. To bring real change into the lives of carers, there must be support services available that meet the needs of the carers, and recognition that these needs will change and fluctuate during the caring journey. As with all support services, early intervention can reduce the need for additional more high intensive supports at a later stage.

## **7. What are some of the principles that should guide investment across ILC streams?**

There are a range of existing services in place in communities that are working well and an important principle for ILC is to build on this existing capital within communities.

Another principle for consideration is that Local Area Coordinators (LACs) are employed by not-for-profit or community organisations or local government. These roles can exist outside of the NDIA and will mean that LACs can be recruited from local communities and not solely from within the Australian Public Service, given there are currently restrictions in place for the recruitment of APS staff.

A final principle to guide investment is not to limit the funding options, but rather to have a range of funding options available. This includes block funding services, competitive tendering and discretionary amounts of funding for one-off intensive supports. In some circumstances competitive tendering will be neither efficient nor appropriate, so other funding mechanisms will be required for certain supports and services.

## **8. How do you see the interface between ILC functions and activities and the interaction with the mainstream service system? (i.e. housing, education, employment, health, family, accessibility and transport)**

While the NDIS is appropriately focused on investing in formal, disability-specific support, without a mainstream service system that can meet the needs of people with

disability there will inevitably be gaps. These gaps can create significant burden for informal carers who may have to increase their caring role and responsibilities, often to the detriment of their own participation, health and wellbeing.

### **9. Other comments (optional)**

As a point of clarification, in regards to the number of carers quoted on page 3 (800,000 as identified by the Productivity Commission):

- These numbers are not referenced, but presumably are taken from the Productivity Commission Disability Care and Support report released in 2011. If this is the case, the Productivity Commission used data from the 2009 Survey of Disability, Ageing and Carers (SDAC). The SDAC survey was also conducted in 2012, and therefore more recent data are available than what has been quoted in the paper.