

## 1. Please tell us your name and organisation

Carers ACT Ltd  
Dee McGrath CEO  
80 Beaurepaire Crescent  
Holt ACT 2615  
E: [dee.mcgrath@carersact.org.au](mailto:dee.mcgrath@carersact.org.au)  
T: 02 6296 9901  
[www.carersact.org.au](http://www.carersact.org.au)

## 2. What are the most important elements of ILC?

As a key voice for carers and caring families in the ACT, we consider that one of the most important elements of ILC is the recognition of the need to provide support to carers and caring families.

We are a NDIS registered provider offering a suite of fee-for-service products to people with disability, and we are a provider of block-funded carer supports.

We are concerned that under 'Access to ILC' (p.3) the Framework states that: *The focus of ILC is not on who will access it, but on the supports offered.*

According to the NDIS Scheme Actuary there are 394,000 carers for people with disability under 65 years of age and 350,000 of these carers are supporting a person with either a severe or profound core activity limitation. Of the projected 410,000 NDIS participants, the majority may have a carer who will require a participant's NDIS Individual Funded Package to include services to sustain their carer's caring role, or they will require access to services through ILC referral. Within the 2.1 million people with disability who are outside the projected NDIS participants many are likely to need to access ILC services, as will their carers.

Carers ACT considers that two important elements in the Framework should be:

- \* how carer assessment and referral to disability and mainstream services are built into the ILC architecture and implementation, and
- \* the management of unmet service demand for services formerly provided through block-funded programs if adequate block-funding is not incorporated into the ILC model.

Carers and caring families require:

- **Access to the right service, at the right time, provided at the right level, and at the right price.** Carers and caring families are over-represented in the two lowest household income levels in Australia, and this is likely to be caring- or disability-related (ABS Surveys of Disability, Ageing and Carers 2003, 2007, 2012). Disability or carer support services are often unaffordable for these carers and under-utilised unless they are accessible through block-funded services. Carers of people ineligible for an NDIS IFP will be further disadvantaged if these services are not readily accessible through block-funded services or specific funds provided to carers and caring families to purchase these.
- **Access to support services to assist them sustain their caring role**, such as residential and flexible respite.
- **Access to specific carer support** – counselling, carer advocacy services, carer social engagement activities (e.g carer support groups, Koori Yarning activities).

- **Access to services that will allow them to engage more fully in employment** – to either commence, maintain or access flexible working conditions, and **education and training** (non carer-related) to provide them with employment opportunities, during their caring period, or once their caring role ceases. Australian Government data indicates that many carers are forced onto Newstart Allowance if they are ineligible for an Age Pension once their caring role ceases. The *Final Report of the Review of Australia's Welfare System* acknowledges this occurrence.

Access to the above support and services fits primarily into the following 'Purpose of ILC Supports':

- ILC supports have a focus on capacity building
- ILC supports enable and strengthen economic and social participation
- ILC and IFPs are not mutually exclusive – Carers ACT considers this purpose essential to provide necessary supports for carers whose needs are not covered by the person with disability's NDIS funded package, and this purpose is covered further in the Framework's 'Intersection with Individual Funded Packages'.

To provide smooth integrated support to people with disability, carers and caring families Carers ACT suggests that a multi-caring service or sector stream is considered as a service delivery option, including assessment to identify multi-caring carers.

This reflects our experience and feedback from carers that one of the things they least like about accessing services is the need to continually repeat their caring story, information about the person with disability, chronic conditions or ageing they care for. *Outcomes of Disability ACT's 2013-14 client satisfaction survey* found that this issue received one of the lowest satisfaction ratings for carers accessing services.

It is encouraging to see the Framework identifies that "... ILC arrangements should be designed to optimise the alignment with mainstream interface areas and preventing the development of parallel systems, particularly aged care (for over 65s) and mental health where participants are not entitled to an IFP" (p.10). Carers ACT suggests that that ILC arrangements should be designed to include carers with multi-caring roles and referral to or engagement with interface areas that meet their increased carer support needs. This may be an extension of the proposed role of Local Area Coordinators who, under the Framework, can provide support to people with low cost support needs and who do not require a long-term relationship with the NDIA (p.12).

See further comments below in Question 3 on carers and caring with multi-caring responsibilities.

### **3. What is missing from the ILC policy framework?**

- Advocacy services for carers – the ACT Government funds the Carers Advocacy Program, which provides carers access to an advocate for their caring related issues e.g discrimination at work due to their caring role, guided support as an advocate through legal caring arrangements. We consider this is an essential component of ILC, particularly as carers are considered a key NDIS partner and their contribution is necessary to ensure NDIS sustainability.

We, and other organisations during ILC Framework discussions, have identified the lack of sufficient information or direction for advocacy services in the Framework.

- Insufficient information about transition from current disability and carer services to an ILC model – what are the priorities for transition, how will transition be funded, what support

will exist for people who fall through current and ILC model gaps (people with chronic condition, mental health issues, or who choose to transition to aged care services).

- The capacity for individuals to access services that may not be included in an NDIS IFP e.g chiropractors, or sufficient provider choice e.g can an individual choose their preferred provider.
- The linkages between disability, health and ageing services and access to necessary services by a carer with multi-caring responsibilities e.g caring for a child with disability a partner with early onset dementia, caring for a child with an NDIS IFP and caring for another child or children with disability who are ineligible to be NDIS participants. We consider this to be critical to support carers in this situation to maintain their caring without further compromising their own health and wellbeing and capacity to continue caring. This will require a mechanism to assess or better understand the impact of a multi-caring role on carers and caring families.

A mechanism to link different service requirements and appropriate assessment for multi-caring carers may become clearer when details about the 'integrated carer support' model being considered by the Australian Government Department of Social Services are available.

- Sufficient recognition of how people with disability and carers will be assessed for ILC referral to capacity building services, or other services that help meet the Framework's objectives to improve economic and social participation. See our comments in Question 2 for more information.

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

Carers ACT agrees with the Framework that the ILC model should be outcomes driven.

Carers ACT suggests outcomes to measure the success of ILC streams in meeting objectives for carers and caring families include:

- was the ILC sufficiently flexible and responsive to the support needs of the person they care for with disability, as well their own needs
- did the cost of services provided through ILC referral or provision prevent them from accessing these services for the person with disability, or their own need
- are there differences in their quality of life and economic and social participation prior to and post NDIS and ILC engagement
- did they or the person they care for with disability have timely access to mainstream services when they were required
- do they have confidence that the person they care for will receive sufficient support, including sustainable, affordable accommodation when they are no longer able to care.

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

Carers ACT considers that key implementation challenges relate to:

- the breadth of the ILC Framework and its aspirations
- how to coordinate or know who or which organisation will provide information and linkages to the ILC population group and their relationship with Local Area Coordinators

- the need for sufficient funding to implement *Stream 1 – Information, linkages and capacity building* services including information/capacity building/gateway resources
- the need for sufficient funding to implement or incentivise *Stream 3 – Community awareness and capacity building* outcomes
- achieving the correct balance between fee-for-service and block-funded programs to ensure that financial disadvantage does not prevent people with disability and carers and caring families accessing services through ILC referral
- managing unmet demand, particularly the availability of a specialist workforce (this is apparent in the NDIS)
- working within the Australian Government’s reform and fiscal constraints – see Questions 8 and 9 for more comments about this issue.

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

Increased independence and opportunities for community involvement through access to relevant information and referral to disability and community services, as well as mainstream services. Also see our comments in relation to carers in Question 4.

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

- A key investment approach should be that investment in ILC programs or activities funded by the NDIA or governments will provide necessary support to those with a high or an increased risk of long-term disadvantage\* because of disability or caring responsibilities. Proposed investment should also consider short-term solutions to prevent crises or meet urgent and immediate needs, with investment in programs or activities that provide early intervention and long-term advantage solutions a priority. This investment approach accords with current reports or other frameworks being considered by the Australian Government, and is an approach introduced by the New Zealand Government.
- Investments should consider equity and cost-effective investment outcomes e.g will a service provide support to a greater number of people with disability, carers and caring families as a block-funded service than if it was delivered as fee-for-service that could preclude people accessing the required service.
- Investment principles should include an outcomes measure to provide evidence if an investment is meeting the needs of the target population.

These proposed principles are important to assist prevent a person with disability’s escalation to an NDIS Tier 3 – IFP participant.

(\*Disadvantage includes lack of independence, no or limited economic participation and no or limited social participation, and low or deteriorating health and wellbeing due to disability or caring responsibilities.)

## **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)?**

Carers ACT considers this interface is critical to achieve the objects of the ILC Framework for NDIS participants, other people with disability and their carers and caring families. Current experience of

many people with disabilities, carers and caring families, and evidence-based reports indicate that the unmet demand for mainstream services (e.g employment or appropriate, affordable and sustainable housing\*) exacerbates risks of homelessness, chronic conditions including mental health issues, family breakdown and poverty etc for this population group.

See our comments in Question 9 below on uncertainty around future funding arrangements. Unless there is sufficient funding available for essential mainstream services the unmet demand will continue with consequential impacts. A significant consequence will be to reduce the realisation of this proposed ILC Framework's objective "...ILC connects to community and informal supports, mainstream service systems and individually funded packages (IFP), to enable an effective integrated response to disability which supports the choice and control of people with disability, their families and carers."

It is important then, that the NDIS is able to monitor and measure the impact of this outcome: "The NDIS can identify and inform areas where governments, in implementing the National Disability Strategy, should focus effort to ensure accessible mainstream supports, programmes and community infrastructure" (p.6).

A challenge for *Stream two: Capacity building for mainstream services* is the Australian Government's fiscal emphasis on stabilising its national budget, debt level reduction and future financial preparedness.

(\*Of the 410,000 projected NDIS participants 57,000 are living in social housing, and there is an estimated 83,000 to 122,000 unmet need for affordable housing, Bruce Bonyhady, 2014.)

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

- In the ACT and other jurisdictions it is unclear how services and activities that form the basis of the ILC Framework will be funded after 2016. As the Framework is not clear about this either and future, unknown policy directions for community and 'mainstream' services will fall out of relevant Australian Government reviews and discussion or white papers (e.g the anticipated NDIA Housing Discussion Paper, the White Paper on the Reform of the Federation) it's difficult for organisations to realistically future plan for their participation in the ILC, their sustainability under this Framework, or to provide adequate informed comment about aspects of the Framework.
- The ACT Government funds Carers ACT to deliver the Carers Voice Mental Health Carers Representation program. We are represented on NDIS implementation groups, have coordinated NDIS information forums for carers of people with mental health issues, and have participated in sector consultations on the NDIS and participation of people with psychosocial disability. An ongoing concern for the mental health sector and mental health carers is where does psychosocial disability fit within the NDIS (partly because it can be episodic), and by correlation within the ILC Framework. There was insufficient information about psychosocial disability in the Framework to address this concern.

Prepared by Colleen Sheen  
Carers ACT Senior Policy Advisor  
13 March 2015