

Carers Australia

Response to Consultation on the NDIS Information, Linkages and Capacity Building Framework (Template for online submission)

1. Name and organisation

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2. What are the most important elements of ILC?

The most important aspect of ILC is clearly that it serves the support needs of the many people with disability who will not qualify for an NDIS Individual Support Package (ISP) and their family and friend carers. While carers have a vital interest in the outcomes of ILC from the perspective of the person/people they care for, they also have an interest from their own perspective. Carers as a cohort tend to have high levels of disability themselves and, whether or not this is the case, they need support to adapt to and sustain their caring role with minimal impacts on their own wellbeing and prospects.

One concern Carers Australia has with ILC is that, because it is aimed predominantly at those people with disabilities who require low levels of support, it may be assumed that their carers also have only low level support needs.

Such a co-relation is simplistic. The support needs of carers are affected by a range of factors, not just the severity of the impairment of the person they care for. These factors include: the age and health of the carer; whether they have a disability, impairment or health condition themselves; their knowledge and capacity to undertake certain caring tasks; and any other caring responsibilities the carer may have for other individuals. It is important that these factors are taken into consideration when determining the type and level of support individual carers need.

Among the elements of the framework which Carers Australia particularly welcomes are the following.

- The recognition that people with disability, their families and carers should be able to access supports consistently across jurisdictions (and, we would add, as far as possible across ASGC-RA locations). This is particularly important in light of the principal goal of the National Disability Insurance Scheme to end the lottery of access to disability support across the country.
- The adaptability of the ILC Framework to respond to the local context.
- The goal of ILC to address the needs of people with disability who may not be currently eligible for an Individually Funded Package (ISP) and to provide early intervention with a view to reducing the future need for more intense supports.

- The commitment to investing in improving community awareness and capacity building (Stream 3) with respect to both people with a disability and family and friend carers. This will be integral to the successful implementation of the National Disability Strategy.
- The flexibility in funding arrangements for ILC, so that funding may be provided through bulk purchasing arrangements, contracts, and short-term grants or through NDIA staff.

3. What is missing?

(a) Clarity and substance

The key difficulty with the framework is that it is written at such a high level of abstraction and generality that it is often difficult to interpret the meaning of some concepts and how they would translate into practice.

Until existing services are mapped, and it is possible to understand what will and won't fall into the ILC ambit under different streams, it is impossible to comment with any degree of confidence on the likely outcomes of the framework and whether it will meet the stated objectives.

Similarly, until funding arrangements are clear (including who funds what and at what level of funding) the capacity of the framework to cover effectively, comprehensively and equitably the support needs of people with a disability who are not eligible for ISPs remains an unknown.

(b) Alignment with other carer policy initiatives

Carers Australia is pleased that the role and support needs of carers are taken into account throughout the framework. On page 8 of the consultation paper, funding and facilitation of carer capacity building and support programmes is mentioned. However, the framework seems to have been written without consideration of other developments which are taking place in relation to policy and programme design for carer supports and services.

Reforms to aged care and the NDIS have exacerbated a counter-productive and artificial distinction between access to supports for carers of people over the age of 65 and carers of people under the age of 65.

This disconnection both undermines economies of scale and scope in the delivery of specialist supports to carers and presents a whole new layer of complexity in coordinating access to supports for "sandwich carers" who may care for one or more aged people as well as a person/people under the age of 65 with disability, chronic illness or mental illness.

The previous government, acting on a recommendation of the 2011 Productivity Commission Inquiry into *Caring for Older Australians* (and repeated in the 2011 *Inquiry into Disability Support and Care*), undertook to introduce Carer Support Centres which would provide a consolidated stream of dedicated carer services regardless of who the care recipient is. However this work lagged behind the major reforms to aged care services and the establishment of the NDIS, and it was not completed before the change of government in 2013. Recently the Department of Social Services at

the request of the Assistant Minister for Social Services has undertaken a new initiative for designing integrated carer supports. The design principles under consideration include:

- An identifiable point of access for all carers.
- A consolidated stream of carer services regardless of who the care recipient is. (An integrated carer support programme would be likely to include, at the minimum: needs assessment; information and referral; emergency respite brokerage and assistance with access to planned respite; counselling; peer support; training and individual advocacy.)
- One carer assessment process
- Encouraging and maintaining innovative approaches to carer support
- Support to engage in, or remain in, education, training or paid work where appropriate.

A separate portal for carers is also under consideration.

The ILC framework, with its strong focus on the under 65s, appears to have been put together without recognition of this initiative and could create roadblocks to its development and implementation.

We note that a similar difficulty arose in aged care with the design of the Commonwealth Home Support Programme (CHSP), which has some similarities with the ILC in that it is targeted at low-intensity, entry level support for aged people living at home. CHSP brings together in one programme a range of former Commonwealth and HACC programmes. These include programmes for carers (which, although designated as aged care programmes, also covered the support needs of carers of people under the age of 65). In recognition that the carer components of CHSP are likely to be transitioned under the integrated carer support model, existing funding for these carer programmes has been extended until such time as the model has been agreed and is ready for implementation.

(c) How will we know the ILC streams are meeting their objectives/vision?

The most obvious approach would be periodical evaluations on a local basis (not just a state or national basis) of the extent to which people with disabilities who do not qualify for packaged supports are able to access capacity building supports they need, and the extent to which mainstream services have become more responsive to the needs of people with disability and their carers.

It would be important to include in this evaluation an audit of service gaps which may have arisen because existing providers have been forced to withdraw their services (often as a result of uncertainties arising in the context of ILC implementation). Such an audit would provide one indicator of the effectiveness of transition arrangements.

It would also be important that these evaluations occur at regular intervals and that the time gaps between them are not so great that it will be very difficult, if not impossible, to address serious failings in the capacity of the ILC to meet its objectives.

4. What would be the implementation challenges?

Until transition arrangements to the full roll-out of ILC are clear, there remains a major concern about how many people with a disability who are not ISP eligible will fall through the gaps in the interim and, indeed, what services will be left to support this group in both the short and long term.

Carers Australia is particularly concerned that many services expected to be provided under ILC will have disappeared while both the NDIS ISPs and the ILC initiative are in the process of being agreed and implemented. This problem is particularly acute in relation to people with mental health problems, since funding for a number of mental health programmes (including Commonwealth funding) has been swallowed up by the NDIS. Many of these services (such as the Personal Helpers and Mentors or PHaMs programme) are very effective for people with mental health problems which have not yet deteriorated to the point where they would be eligible for an individually funded package of supports. In other cases, the viability of mental health services has become increasingly uncertain as contracts approach their end and future funding is uncertain. (See Mental Health Australia, *Continuity of Funding Survey*, November 2014, <http://mhaustralia.org/publication/continuity-funding-survey-glance>)

Carers Australia has similar concerns with respect to DSS programmes to provide respite support for young carers and the Mental Health Respite: Carer Support programme. Under initial NDIS bilateral arrangements, funding for these programmes was designated for transfer to the NDIA to contribute to ISPs. Indeed, we have no idea how respite services will be encompassed by ILC since they are not mentioned under the list of examples of individual capacity building services identified under Stream 4.

We strongly support the case put by National Disability Services (NDS) in its submission that existing contracts should be rolled over (and funding may need to be topped up in some cases) while services are being mapped and evaluated and gaps are identified. This would include carer services contracts. In addition, providers must be informed well in advance about future funding structures if they are to transition smoothly to the new framework.

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

Clearly, it depends on the person.

Perhaps the most obvious generic example to be drawn from the framework is that services may avert or retard deterioration in the person's condition and/or living situation – including that of carers. If the interfaces with mainstream services become more effective than they are now, it may also assist people with disabilities and their carers to avoid some of the negative concomitants of coping with a disability or caring for someone with a disability. These include social isolation, an inability to engage in education or employment, problems finding housing, difficulties accessing transport and so on.

The ILC will also be important to providing ongoing support to people with severe and profound disabilities who are waiting for the NDIS to come to their location or who are queued for Tier 3 support in trial sites.

Feedback from the NDIS trial sites indicates that the steps involved in applying to the Scheme, going through the planning process and accessing supports can be lengthy.

Data from the latest NDIA Quarterly Report to the COAG Disability Reform Council showed that overall, the average number of days between when an access request is made and support is approved for 2014/15 was 72 days. The average length of time from application to the commencement of services is even greater, with a total average of 100 days across all trial sites.

While the current administrative processes in the system will undoubtedly improve as the NDIS rolls out, it is important that the implications of lengthy delays are taken into account in designing the ILC component of the Scheme.

There is also scope to consider whether ILC could potentially be used as a fast-tracked approach to providing supports for people with quickly deteriorating conditions, or where the impact of any potential delays will be significant.

6. What are some of the principles that should guide investment across ILC streams?

Carers Australia supports the recommendations of National Disability Services' (NDS) response to this section of the ILC framework. This includes:

- Valuing local networks and social capital production.
- Promoting collaboration on infrastructure and 'back of house' services.
- Rewarding quality services.
- Bulk purchase where it is impractical to rely on individualised funding. (As the NDS points out in its submission, block funding through grants, seed funding or competitive tender processes will be appropriate for most ILC services.)
- Provide continuity and longer-term contracts so that scarce resources are not diverted to complex tendering processes on a frequent basis and there is sufficient space for services to effectively plan and innovate.