



Carers Australia

**Submission to the Information, Linkages and
Capacity Building Commissioning Framework –
Consultation Draft**

April 2016

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability,
- chronic condition,
- mental illness or disorder,
- drug or alcohol problem,
- terminal illness,
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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

Carers Australia is part of the National Network of Carers' Associations (the Network), which is made up of the Carers Association for each State and Territory. The Network works collaboratively to lead change and action for carers across Australia. Our shared vision is of an Australia that values and supports all carers.

The Network is supportive of the introduction of the Information, Linkages and Capacity Building (ILC) component of the National Disability Insurance Scheme (NDIS). In addition to broadening the support available to NDIS participants, ILC will extend some benefits of the NDIS to non-participants and to the families and carers of both groups. This is particularly important given that the funding for many carer support programs is in scope for the NDIS, but the supports available to carers in NDIS plans have fallen short of our expectations.

We had hoped that the ILC may address some of the gaps emerging in carer support as a result of the disability reforms, and were pleased to see a strong representation of carer supports in the ILC Policy Framework. However, the scope of carer specific support in the draft Commissioning Framework appears to be significantly reduced from initial indications. While the Integrated Plan for Carer Support Services currently being developed by the Department of Social Services (DSS) promises to ensure carer needs are recognised and supported in the wake of disability reform, very little information is available about what it will actually provide, and whether it will replace the service types that are not being replicated within the NDIS.

It also remains unclear to what extent carer specific supports will be prioritised in the tendering for ILC grants, given the focus on outcomes for the person with disability and the relatively small amount of money which will be available on an incremental basis as the NDIS rolls out nationally.

Following what we felt was an inadequately short co-design period in late 2015, the Network commends the National Disability Insurance Agency (NDIA) on its decision to extend stakeholder consultation on the draft Commissioning Framework. We urge the NDIA and DSS to work with the State and Territory governments to ensure that potential gaps in carer support are addressed through either NDIS plans, the ILC or the Integrated Plan for Carer Support Services, or a combination of all three. Our priority is to ensure that existing expertise and successful programs in the carer support sector are not lost in the transition, so that no carer is worse off, and to ensure that all carers have access to supports in their own right, regardless of the age or condition of the person they care for.

Introduction

- Carers Australia welcomes the decision of the National Disability Insurance Agency (NDIA) to release a draft *ILC Commissioning Framework* and to seek input from both the public and the sector. The timeline for consultation on the *Commissioning Framework* is appreciated, particularly in the wake of the somewhat rushed co-design process of 2015.
- Carers Australia supports the five priority investment areas identified in the *Commissioning Framework*. We believe these areas provide a sound framework for funding priority when applied with the five activity streams identified in the *ILC Policy Framework*.
- The inclusion of an ILC outcome that focuses on carers is also welcomed, along with the identification of carers as a potential cohort under the priority investment area of 'cohort-focused delivery'.
- In the context of what may be a complex application process to gain funding through ILC, Carers Australia also welcomes the efforts of the NDIA to identify ways to help build the capacity of the sector to shift to an outcomes based approach. Organisations will have different levels of capacity to make this change, and any assistance provided by the NDIA will be particularly important to help smaller organisations successfully apply for funding through ILC.

Areas of uncertainty

The role of Local Area Coordinators VS ILC:

- The *ILC Commissioning Framework* gives clear direction that ILC activities must complement not duplicate the role of Local Area Coordinators (LACs). However, discussions among the Carers Network illustrate there is some confusion around exactly what the scope of LACs is, and to what extent this might vary across different regions due to differences in support needs and service gaps.
- Clarity around the role of LACs and any differences in their responsibilities across regions will be essential to assist organisations to identify supports that may be funded through ILC in their area.

Outcomes for carers under ILC:

- The Commissioning Framework lists 9 outcomes, one of which is specifically relevant for carers: “*Informal support and care arrangements are upheld and nurtured*”. This outcome has been drawn from the NDIS Strategic Plan¹ which states: “Recognise, nurture and uphold informal support and care arrangements, especially for children and vulnerable adults”. (p.6)
- It is not immediately apparent to Carers Australia what ‘upheld and nurtured’ would mean in a practical sense for carers. There are a range of sub-elements that could potentially sit under this broad carer outcome that would be more definitive and measurable. These could include:
 - knowledge and capacity to effectively undertake the caring role;
 - health and wellbeing of the carer;
 - sustainability of the caring relationship;
 - social and economic participation of the carer.
- We also note that the carer outcome in the *Commissioning Framework* appears to differ slightly from the relevant sections for carers under the NDIS Act:
 - Part 2, Section 4 (12) “The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected”. (Emphasis added)
 - Part 2, Section 5 (d) “the supportive relationships, friendships and connections with others of people with disability should be recognised”. (Emphasis added)
 - Part 2, Section 5 (f) (iii) “strengthen, preserve and promote positive relationships between the child and the child’s parents, family members and other people who are significant in the life of the child”. (Emphasis added)
- The *ILC Policy Framework* also suggested an outcome for carers under ILC: “sustaining families and carers in their caring roles” (p.20), which also differs slightly from the outcome in the *Commissioning Framework*.
- At the Carers Australia National Carers Conference held in November 2014, Bruce Bonyhady, the NDIA Chairperson reported that there would be five key outcomes for families and carers under the NDIS:
 1. Families/carers have the support they need to care.
 2. Families and carers know their rights and advocate effectively for the person they are caring for.
 3. Families and carers are able to gain access to desired services, programs and activities in their communities.
 4. Families and carers have succession plans
 5. Parents and carers enjoy health and well-being.²

¹ <http://www.ndis.gov.au/about-us/information-publications-and-reports/Strategic-plan-2013-16>

² http://www.ndis.gov.au/sites/default/files/documents/bonyhady_speech_careers_conference_nov14.pdf

These 5 outcomes are also reflected in the 6 ‘family domains’ identified in the NDIS Outcomes framework pilot study summary report³ (see table below).

Family domains

DOMAIN	0 TO 15	15 TO 24	25 AND OVER
1	Families understand their children’s strengths, abilities and special needs	Families understand their young person’s strengths, abilities and special needs	Families have the support they need to care
2	Families know their rights and advocate effectively for their children with disability	Families know their rights and advocate effectively for their young person with disability	Families know their rights and advocate effectively for their family member with disability
3	Families help their children develop and learn	Families help their young person become independent	Families are able to gain access to desired services, programs, and activities in their community
4	Families feel supported	Families feel supported	Families have succession plans
5	Families are able to gain access to desired services, programs, and activities in their community	Families are able to gain access to desired services, programs, and activities in their community	Families enjoy health and wellbeing
6	Families enjoy health and wellbeing	Families enjoy health and wellbeing	

Source: NDIS Outcomes framework pilot study: summary report pp.10-11⁴

- Each of the outcomes identified for carers in the *Commissioning Framework*, the *Policy Framework*, the NDIS Act and the NDIS Outcomes Framework are slightly different. There are both advantages and disadvantages to the different language used to describe outcomes for carers across these documents and there will no doubt be varying opinions on the relative value of carers being ‘upheld and nurtured’ versus ‘acknowledged and respected’ or ‘recognised’.
- There is an advantage to be gained in having greater consistency across these documents, both in providing greater clarity to people with disability, families and carers and to the Agency itself. Carers Australia believes the key importance in identifying outcomes for carers through ILC, and indeed through the broader NDIS are dependent upon ‘unpacking’ what the outcomes actually mean in practical terms of carer access to specific services and supports within the NDIS.
- Outcomes for carers under the ILC could also be drawn from The Statement for Australia’s Carers contained in Schedule 1 of the *Carer Recognition Act 2010*⁵.
- As the *Commissioning Framework* identifies, there will be difficulties in measuring some outcomes for people with disability. So too are there likely to be similar challenges in measuring outcomes for carers, as there will be many factors which impact on whether a

³ <http://www.ndis.gov.au/document/outcomes-framework-pilot>

⁴ <http://www.ndis.gov.au/document/outcomes-framework-pilot>

⁵ <https://www.legislation.gov.au/Details/C2010A00123>

funded carer support has achieved its objective. For example, the extent to which the wellbeing of a carer has been improved through the provision of peer support will be influenced by factors such as whether the carer cares for more than one individual, whether the condition of the person/s they care for are stable, whether the carer has access to other supports and services, and the impact of the caring role on their economic and social participation.

Identifying gaps in support:

- As one of the aims of ILC is to address service gaps, there will be a need for clear information from the regional or even local level on what types of services are needed in different areas and what the relative demand is. This information will be crucial for those identifying which activities should be funded under ILC in different areas, particularly if the type of community development work undertaken by LACs differs across regions.
- An initial source of this information may come from the market scan to be undertaken by the NDIA, the findings of which may also prove useful to organisations who are applying for funding under ILC.

Other comments

Data collection:

- Carers Australia has been disappointed that the NDIA has not been systematically collecting data on whether NDIS participants have a carer/s and whether that person/s has received support through the NDIS package of the person they care for, despite funding for carer support programs being transferred into the NDIS.
- We understand that some individuals who receive support through ILC will have minimal contact with the NDIA (if at all) in comparison to those who have an NDIS package, and therefore there will be limited opportunity to capture data for some individuals through ILC. However, there will be others for whom there is greater opportunity to gather data under ILC-funded activities, and it is our hope that at a minimum, this would include whether the person accessing a service has a carer, or is a carer themselves.
- Carers Australia was pleased that the development of the NDIS Outcomes Framework has included questionnaires for families and carers. Our hope is that any Outcomes Framework developed for ILC also includes a carer-component. However, there are areas that could be improved from the NDIS Outcomes Framework if a similar approach was used for an ILC outcomes framework. For example, while there are questions which explore the desire of families and carers to work and the barriers they experience to working more, the questionnaire does not specifically ask whether supports delivered through the NDIS have actually helped in this regard. In the context of assumptions that the NDIS will see many carers return to employment, capturing better data on this question is of high importance.

- The introduction of the Carer Gateway by DSS in December 2015 also opened up new possibilities for gathering data on carer access to information and supports as well as referral pathways. Carers Australia sees value in establishing systematic recording of referrals from the NDIS (be it through ILC, an LAC, or the NDIA) to the Carers Gateway and vice versa.

Support for carers:

- The Commissioning Framework identifies 3 areas of carer support:
 1. Linking carers and families to existing social and recreational activities that give carers a break from their caring role and connect them with the community.
 2. Activities that promote carer wellbeing such as personal development, peer support and mentoring.
 3. Linking carers into direct carer support services.
- The fact that activities 1 and 3 are described as 'linking' leads us to assume that they won't involve new funding, but are merely referral to existing services outside of the NDIS.
- The *Commissioning Framework* makes it clear that activities will only be funded for carers under ILC "to the extent that those activities benefit people with disability and increase their social and economic participation" (p.16). While many supports for carers ultimately improve their capacity to provide care, and will therefore benefit the person with a disability, it remains to be seen how this criterion will be applied in practice, and to what extent organisations would be required to measure and prove this benefit. There is potential for this to prove quite difficult if it required all organisations providing services to carers to also have direct contact with people with disability.
- There is also a discrepancy between the types of carer supports described in the *ILC Policy Framework* and those described in the *ILC Commissioning Framework*. For example, the *Policy Framework* states that examples of individual capacity building supports may include: "parent breaks and programs to provide parents with skills and information about disability" (p.13) (emphasis added). However the *Commissioning Framework* states that the ILC "will be unlikely to fund recreational activities for families or carers, such as holidays or camps, through ILC" (p.16). It is unclear what types of carer programs would be categorised as a 'parent break' as opposed to 'recreational activities', particularly if they included an educational and training component. It is also unclear whether the definition of a 'parent break' automatically excludes similar supports for carers of family members other than children, for example carers of a partner. Further clarity on these distinctions will be required before organisations providing carer supports are able to apply for ILC funding.
- Considering the narrow scope for carer supports under ILC, and that carers are not participants of the NDIS and therefore have no right to access supports within the Individually Funded Plan of the person they care for, Carers Australia remains concerned that funding for carer supports continues to be transitioned into the NDIS.
- In particular, we are concerned about the planned full transition of funding for the Mental Health Respite: Carer Support programme (MHR:CS), and the partial transition of

funding for the Young Carer Respite and Information Services Activity (YCRIS) into the NDIS. Carers previously accessing support under these programmes have no guarantee that they will continue to receive the same level or type of support through the NDIS plan of the person they care for. Indeed feedback from trial sites indicates some carers are already losing access to supports they previously received through these programmes as the person they care for transitions into the NDIS.

- The transition of funding for these programmes into the NDIS is also of concern for those who care for someone who isn't eligible for funded support through the NDIS, with ineligibility rates for applicants with a mental illness significantly higher than those resulting from applications from people with physical, intellectual and sensory disabilities.⁶ It is hoped that the identification of both carers and people with mental illness as potential groups to be supported through 'cohort-focused delivery' will provide opportunities for mental health carers to access support through ILC.
- As the Government continues its work to develop a new system of Integrated Carer Supports we are also concerned that there will be little funding remaining outside the disability and aged care systems to support carers in their own right, regardless of the age or condition of the person they care for. The interaction between the aged care system, the NDIS (including ILC and LAC components) and the new service landscape of Integrated Carer Supports will also require further policy development. For example, the extent to which access to supports within one system effects entitlements within another remains to be seen.
- There is also ongoing concern across the Network that state governments will continue to reduce their own responsibility to fund disability and carer supports outside the NDIS. This is particularly worrying for those who care for someone who is not eligible to receive funded supports through the NDIS, but who still have considerable care needs. In this context it is worth noting that according to the Australian Bureau of Statistics, some 1.39 million Australians have a disability that is categorised as having a severe or profound limitation on core-activities,⁷ while approximately 460,000 people are expected to receive funded supports through the NDIS.

⁶ NDIS Independent Advisory Council, 'IAC advice on implementing the NDIS for people with mental health issues', <http://www.ndis.gov.au/about-us/governance/IAC/iac-advice-mental-health>

⁷ Australian Bureau of Statistics, 2012 Survey of Disability, Ageing and Carers