ILC Commissioning Framework - written feedback form

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State/territory	National
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1. The proposed outcomes for ILC and the best ways to measure them

Questions you might like to consider:

- Do you agree with the nine outcomes outlined in the Consultation Draft? Is there anything else the Agency should consider?
- Do the nine outcomes cover everything you would expect to see in ILC?
- How should we measure each of the nine outcomes?
- How can people with disability, their families and carers and the broader community stay involved in measuring outcomes as ILC rolls out?
- Is there anything we should consider in setting up our data collection processes?
- Is there anything else you would like to tell us?

Do you agree with the nine outcomes outlined in the Consultation Draft? Is there anything else the Agency should consider?

Alzheimer's Australia supports the nine outcomes outlined in the Consultation Draft which ensure a focus on choice, independence, participation, community awareness and access to appropriate supports. An additional outcome should be considered, to support access to a timely diagnosis, and to appropriate services and support during the period between commencement of symptoms and delivery of a final diagnosis. This is particularly relevant to people with progressive neurological conditions such as people with Younger Onset Dementia (people with dementia aged under 65) where the diagnostic process is lengthy, with some taking over seven years to achieve a correct diagnosis.

Do the nine outcomes cover everything you would expect to see in ILC?

The nine outcomes provide a broad policy direction which is consistent with the views of Alzheimer's Australia and the approach of our Younger Onset Dementia Key Worker Program. This program provides one-to-one support from the point of diagnosis throughout the dementia journey. Key workers link clients to early intervention supports and services and build capacity in families and clients to remain independent for as long as possible. The benefits of early intervention are well known and integral in ensuring the person living with dementia remains engaged, independent and maintains a good quality of life for as long as possible following a diagnosis. The key workers also work within the service sector to develop dementia-specific services and supports.

The outcomes should be expanded to recognise the role of ILC in supporting both the person with the disability but also the family and informal carers. Alzheimer's Australia welcomes the aim of the ILC to build capacity of families and carers to sustain them in their caring role, for example linking them to support services, providing personal development, peer support, and mentoring. Families/informal carers are of immense importance in supporting many people with dementia, including those with younger onset dementia, and face many challenges. The outcomes should recognise and be inclusive of the need for support for families/carers.

In addition, it is essential that the ILC meets the needs of people with younger onset dementia and others with progressive neurological diseases, including the need for specialised supports (e.g. dementia services) which may no longer be available through mainstream services or the NDIS. The consultation draft notes the importance of ILC working well with the aged care system, and recognises that some services work both with people with a disability under 65, and with people over 65. Alzheimer's Australia notes the importance of ensuring continuity of service and support for people who have younger onset dementia and then reach the age of 65: these people should not fall through the gaps between disability programs and aged care programs.

How should we measure each of the nine outcomes?

The measurement of outcomes for the ILC is a complex task that requires consideration of the different outcomes that might be expected for different types of disabilities. For example, for a person with a progressive neurological disability it would be unwise to expect to see a positive change in independence and social/economic participation in all cases. In fact, a smaller rather than larger decline in participation, or stability over time, may constitute success in some cases, as without support the progressive nature of the disease can mean that people may lose all ability to be independent and to participate.

Alzheimer's Australia welcomes a focus on goal achievement of clients (p.42) as this will take into account outcomes that are achieved through a combination of a number of different areas of support, and measures the outcome that is most important to consumers. This is the approach that we have taken within our Younger Onset Dementia Key Worker Program and have found it to be successful in supporting both outcome measurement and care planning. It is essential that the goal-setting process is done carefully to ensure realistic, achievable goals which will result in meaningful outcomes for consumers.

The outcome measurement should include additional measures to assess how promptly clients are supported. This is essential for clients with degenerative conditions who may have only a small window of time in which they will benefit from early intervention or be able to participate fully in planning.

It is also essential that in measuring outcomes, success is defined not only by participation level, but also and very importantly by measuring the satisfaction and quality of that participation. For example on p 44, the proposed approach to measuring increased community/mainstream awareness and knowledge of how to support people with disability includes measuring the percentage of assisted individuals who take part in mainstream activities (of various types). People with younger onset dementia or any other form of disability may participate in a mainstream activity or community group, but may be very dissatisfied with the support provided, and encounter staff who do not understand their condition. In the current measurement framework this would be considered a success because they are involved in the activity, but no consideration would be given to whether this participation was meaningful or provided the person with a sense of satisfaction.

How can people with disability, their families and carers and the broader community stay involved in measuring outcomes as ILC rolls out?

Consumers and carers should be involved in setting and reviewing outcome measures and being surveyed as part of measurement of user experience. This involvement is essential to ensure that outcomes are measured that are meaningful to consumers and that the services are targeted to support consumers to meet their needs. Focusing outcome measurement, where possible, on goal attainment enables consumers to have a clear role in setting out what should be measured and identifying whether it has been achieved.

Is there anything we should consider in setting up our data collection processes?

The development of measures and data collection methods should be undertaken in partnership with consumers and carers. Outcomes for those with degenerative diseases/disabilities (e.g. younger onset dementia) will be considerably different to those with stable neurological disabilities and those with physical disabilities. Data collection and analysis must take into account these differences. In order to get a complete picture of the experience of consumers, qualitative data/information should form a part of the data collection and outcome measurement.

2. How to prepare the sector for outcomes-based performance measurement

Questions you might like to consider:

- What are the biggest challenges for organisations moving to outcomes based funding?
- What can the Agency do to help organisations meet those challenges?
- What can people with disability, their families and carers do to help organisations get ready?
- Is there anything else you would like to tell us?

What are the biggest challenges for organisations moving to outcomes based funding?

The consultation draft notes on p.26 that the ILC Commissioning Framework is not suggesting a pure "outcomes based" funding model. Instead the approach is focused on competitive sourcing which will consider principles of equity, efficiency, effectiveness, and transparency. The NDIA should be commended on focusing on an approach that will lead to cost-effective support for consumers. The challenge is ensuring that appropriate supports are in place for organisations moving from block funding to a more competitive sourcing approach, and ensuring that the expertise which has been built up by organisations is not lost, particularly for specialist services.

The gap in ILC funding between the end of block funding arrangements and the start of the outcome based competitive funding (due to roll out officially in 2019-2020) presents a challenge for organisations that are already working to build capacity for their consumers and maintaining existing initiatives that will fall under the ILC umbrella. There is a danger that this funding gap will lead to a loss of specialist capacity in the sector. In addition, a lack of certainty about ongoing funding raises concern for the maintenance of ongoing relationships with community organisations, consumers, and service providers.

The ILC framework should take into account the unique challenges of consumers with conditions that require specialist support such as degenerative neurological disabilities. Outcomes based funding could potentially see the ILC focusing on projects with clear, short-term, easily quantifiable and uncomplicated outcomes that may only benefit a section of the consumer base. This could potentially come at the expense of pursuing outcomes for consumers with more complex needs that may take longer to achieve.

What can the Agency do to help organisations meet those challenges?

As outlined in the Draft Framework it is essential that the new funding process does not disadvantage smaller providers or create a loss of specialist knowledge and capacity. The staged approach outlined will be essential to this process. Additional support that should be provided includes:

- Interim block funding to support ongoing ILC activities.
- Assessment of proposals should include a consideration of the supports and relationships with consumers that existing service organisations have developed and the potential cost and service-benefit of continuing with an established provider.
- Assessment of proposals should also include recognition of and appropriate responses to the unique challenges raised by degenerative neurological diseases (e.g. younger onset dementia).
- Safeguards are required that ensure ILC funded activities are maintained and continue to be appropriate for the consumers for whom they were originally implemented. This may involve developing and implementing quality frameworks,

What can people with disability, their families and carers do to help organisations get ready?

People with disability, their families and carers can educate themselves about the changes and advocate for the ILC activities they believe will help them the most. It is important that the NDIA plays a role in informing people with disability, their families and carers about ILC, the time it will take to set up the ILC outcomes based funding grants and what this means for them.As part of the grant application process, providers should be asked to provide evidence of past experience in achieving success in promoting choice, independence and quality services. Consumers and providers could work together to document the areas of previous success and how they can be translated into the new ILC approach.

3. How to grow social capital in the sector, particularly volunteering

While there are many different definitions of social capital, in this context social capital means things like volunteering or the relationships that organisations have with others in the community that contribute to the work of the organisation and help people with disability and their families.

Questions you might like to consider:

- The Agency would like to see things like volunteering grow in ILC. What can the Agency do to make sure that happens?
- What barriers might there be to growing social capital?
- What types of activities work well when delivered by volunteers?
- Is there anything else you would like to tell us?

The Agency would like to see things like volunteering grow in ILC. What can the Agency do to make sure that happens?

Utilising volunteers within ILC is a good strategy but will only be successful if the appropriate supports are in place. For example, volunteers require induction training, ongoing support and debriefing opportunities, and should be compensated for any out-of-pocket expenses. Paid staff are required to recruit, train, monitor and manage volunteer workforces. One strategy that may be successful is reaching out to people who have previously been informal carers for family members or friends. Often once the caring responsibility is finished, people want to share the expertise and experience they have gained in supporting someone with a disability. Alzheimer's Australia is a strong proponent of peer led programs and is well positioned to build and provide managerial support for peer led volunteer programs.

What barriers might there be to growing social capital?

For social capital growth to be sustainable and effective it requires organisations to manage and maintain stakeholder networks. There needs to be a strategic investment and support to harness the potential of volunteers and other stakeholders. The Agency should look to established organisations (e.g. Alzheimer's Australia, MS Australia, MND Australia) that have the relevant experience and resources required to drive and maintain growth in social capital within their particular disability/disease networks.

What types of activities work well when delivered by volunteers?

Social groups, support groups, one to one support, guidance through diagnosis, disease management and progression are activities that work well when delivered by appropriately trained and skilled volunteers. Alzheimer's Australia has a wealth of experience in providing training and up-skilling of volunteers to enable them to provide safe, appropriate and effective peer support, leadership and education.

4. How to prepare the sector for the requirements of the ILC sourcing process

The Agency is moving to a nationally consistent framework for ILC. Funding will be provided to organisations through an open competitive grants process.

Questions you might like to consider:

- What are the biggest challenges for organisations moving to competitive grant funding?
- What can the Agency do to help organisations meet those challenges?
- Is there anything else you would like to tell us?

What are the biggest challenges for organisations moving to competitive grant funding?

Some of the challenges facing organisations moving to competitive grant funding include:

- o There is a concern that when competing with highly resourced private organisations, smaller organisations may miss out on competitive grant funding despite their experience in providing cost-effective services and understanding the needs of their clients. The consultation draft notes these concerns but it is essential that appropriate support is provided in the implementation of ILC. NDIA needs to carefully consider the weighting of the elements/areas within their grant applications and ensure intended tender outcomes tie back into consumer need/outcomes.
- o Competitive grant funding may result in slightly more expensive but more holistic and consumer-directed programs being passed over for less expensive but less comprehensive ILC programs. It is essential that outcomes for consumers are at the centre of decision making around grant funding, and that funding decisions are based on cost-effectiveness rather than simply on price.
- o Similarly, certain consumer cohorts may not be identified as priority areas for funding despite clear needs within this cohort.
- o There is a concern that competitive grant funding may focus only on supports for people who have a clear diagnosis and documented disability. Some conditions require a lengthy diagnostic process before the disability is clearly documented. Currently, early support is often available through block funded services and it is essential that this remains the case under ILC competitive grant funding.

5. Rural and Remote

The Agency would like to make sure that ILC meets the diverse needs of people with disability across the country.

Questions you might like to consider:

- What does the Agency need to consider when rolling out ILC in rural and remote areas?

- How can we encourage and support growth in ILC type activities in rural and remote areas?

- What things work well in supporting organisations working in rural and remote areas?

- Is there anything else we need to consider?

- Is there anything else you would like to tell us?

What does the Agency need to consider when rolling out ILC in rural and remote areas?

It is essential that NDIS provides access to equitable services for people with disabilities living in rural and remote communities. The cost of providing services in these areas will be much higher than in urban areas, but this should not diminish the level of service provided. Experience from the implementation of Consumer Directed Care for home care packages within the aged care sector has demonstrated that individualised funding models can be challenging to implement in rural and remote areas due to additional costs leading to reduced access to service hours.

Although the use of technology is an attractive solution, it is essential to consider whether this is appropriate and supports the needs of consumers. People with younger onset dementia, for example, have indicated a strong preference for face-to-face support through a key worker. At the same time, it is essential that ILC services are sustainable and cost-effective. Appropriateness to the region and population is also a vital consideration when rolling out ILC in rural and remote areas.

How can we encourage and support growth in ILC type activities in rural and remote areas?

The identification of remote/rural delivery as one of the five investment areas will assist in supporting development of ILC activities. It may be beneficial for the NDIA to develop a network of remote/rural providers who can share best-practice and innovative models of service delivery. As part of this capacity building approach, a scan of existing successful ILC type activities in rural and remote areas that could potentially be expanded to other activities and areas would be helpful.

Due to the nature of the geography and client base, rural and remote providers may need to support a broad range of different types of disability clients. Therefore it is essential that they have access to training and information to enable them to provide the specialist services required.