

## Office of the Public Advocate

### Feedback on the National Disability Insurance Scheme Framework for Information, Linkages and Capacity Building

While I am highly supportive of the underlying premises upon which the need for an Information, Linkages and Capacity Building Framework (hereafter referred to as the ILC Framework) is based, I am concerned that its success will be jeopardised by poorly developed local infrastructure in many areas of Queensland, and the lack of cohesion across service systems, inclusive of the private and not-for-profit sectors, as well as local, state and federal Government departments and agencies. From my understanding, this issue is not limited to Queensland.

The success of the ILC framework is also reliant upon attitudinal acceptance and the willingness of communities to be responsive to the needs of people with disability, and to provide resources to respond to issues impacting people with disability and support the activities that may need to be pursued, for example the growth of local infrastructure and/or improved accessibility.

While it is this very issue that the ILC Framework is ostensibly being put in place to remedy, the resourcing that is likely to be required to attend to these limitations, particularly in regional, rural and remote locations, may in and of itself be a barrier to effective implementation of this strategy.

I am also concerned that insufficient attention is being given to reviewing and strengthening the regulatory environment in the states/territories in view of the transition to the NDIS. Ensuring an appropriate and more contemporary head of power to mandate responsiveness to issues impacting people with disability will provide for ongoing accountability, promote an ongoing focus on making reasonable accommodation and ensure that commitments aligning to the National Disability Strategy are upheld post the full implementation of the NDIS.

The ILC Framework states that “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”. Without a guiding legislative mandate at the state/territory level to ensure that the resourcing of such recommendations is appropriately prioritised, there is a risk that they may not be attended to in a timely manner, which could undermine the success of local initiatives in achieving much needed change outcomes at both individual and systemic levels.

For example, the NDIS might recommend improvements to transport and travel in a local community to enable wheelchair users to safely navigate without the need for additional support (eg pavement upgrades, accessible buses/taxis, building ramps, etc). If such improvements are not attended to, then it is likely that people with disability will still require access to individual funding (ie will need to become a NDIS participant) to assist them with accessing the community.

There is also a clear need to ensure that any legislative, policy, programmatic and other infrastructure appropriately considers the needs of people with impaired decision-making capacity, particularly with respect to any additional supports that may be required to enable the accessibility and responsiveness of local initiatives and ensure benefit for people with impaired decision-making capacity.

A more detailed outline of key issues is provided on the following pages.



## Legislative, strategic policy and programmatic infrastructure support

- Given the focus of the ILC Framework is on influencing and shaping supports at a systemic level, there is a need to not only focus on individual support, but also the infrastructure that is required at a strategic policy and programmatic level to enable a systemic focus.
- Without a strategic policy and programmatic infrastructure there is a real risk the ILC service streams will be neither evidence-based nor effective in achieving systemic changes/outcomes.
- Currently this is achieved by the Commonwealth and states/territories acting through the National Disability Strategy 2010-20 (NDS) – this strategy however is reliant upon the existence of strategic policy and programmatic responses by state/territory governments.
- While legislation (such as the *Disability Discrimination Act 1992* (Cth)), the UN Convention, and the NDS may be important enablers, they require infrastructure in order to be operationalised.
- The combined Commonwealth and state infrastructure currently play an important role, but these efforts will need to be strengthened to achieve the outcomes and efficiencies sought under an NDIS.
- These elements are not currently clear under the ILC Framework; neither is their importance well articulated.
- At minimum, Queensland legislation, as with other states/territories, will need to move from the regulatory space (regulating disability services) to the aspirational space (ie promoting and mandating inclusiveness and reasonable accommodation).
- For example, the NSW Government has recently reviewed their disability legislation and has introduced the more visionary/aspirational *Disability Inclusion Act 2014*, which has the dual aims of both regulating disability support services (until the transition to the NDIS) and ensuring that mainstream services are accessible and responsive to people with disability.
- While the need for certain outcomes is identified in the ILC Framework, the infrastructure necessary to enable this to be achieved is not described.

### Important Questions:

- How will state/territory and Commonwealth governments continue to work together at a strategic level to achieve the priorities identified under the NDS?
- What resources will be directed from the state and Commonwealth levels toward strategic policy and programmatic responses?
- Who will take responsibility and what resources will be developed to enable evidence-based research including evaluation of programmatic responses to measure the success of the ILC supports?
- Will (and how will) state governments move from the regulatory space (regulating disability support services) to the aspirational space (promoting inclusive communities and mandating reasonable accommodation from state government agencies such as education, transport, health and housing)?

## Stream one: Information, linkages and referrals

- Ensuring people with disability, particularly people with impaired decision-making capacity, have the information and support they need to link to the services they need (both mainstream and disability specific) is not done particularly well under the current system due to a lack of integration and coordination, particularly between disability support systems and other mainstream services.
- Another current issue is that people often receive information from one source directing them to mainstream or other service systems, only to find themselves cycling between systems due to there being insufficient resources to provide the service that is required.
- A particular example for people with impaired decision-making capacity, who often have complex health and other support needs, is the lack of integration between health and disability support services, and the limited services provided in some community settings.
- This has had a number of impacts including:
  - People with disability being ‘stuck’ and isolated in health facilities, aged care facilities, and congregate care facilities; and
  - An increased need for guardianship arising from the need for someone to assist people with disability to navigate increasingly complex service systems and/or access much needed supports. In such cases, guardians often find themselves taking on a case management role/linkage role (which may not always be the most appropriate solution).
- People with impaired decision-making capacity will need individual assistance (but not necessarily paid for from their individual support packages) in navigating the systems and accessing NDIS supports.
- At the same time, the systemic work needs to be undertaken to ensure better integration and coordination across services.
- For these reasons, any strategies for information, linkages and referrals must be cognisant of the needs of people with impaired decision-making capacity, and be appropriately designed to ensure their accessibility accordingly.
- The *Local area coordination* service stream would potentially be a good avenue through which the *Information, linkages and referrals* service stream could be facilitated.

### Important Questions:

- What policy and programmatic infrastructure will support the integration and coordination of key systems?
- What programmatic funding will be available to support system linkages and increase the resourcing of mainstream and community supports and services?
- How will information be targeted and accessible to people with impaired decision-making capacity?
- How will people with impaired decision-making capacity be supported to understand the information that is available and make decisions about the support services (both disability and mainstream) that they need to access?

## Stream two: Capacity building for mainstream services

- Building the capacity of mainstream services to respond appropriately to people with disability is crucial.
- The ILC Framework states that the NDIS will identify issues at a local level to inform government responses under the NDS.

### Important Questions:

- Who will identify issues at the local level and what will be the mechanisms for informing the development of strategic policy such as the NDS and programmatic responses?
- Who will coordinate and deliver the strategic policy and programmatic responses aimed at capacity building for mainstream services?
- How will the success of these strategies be measured?
- Who will carry out the evaluations and how will this be used to contribute to and enhance evidence-based research?

- While strategic policies such as the NDS are important, in addition to other enablers such as the UN Convention and the *Disability Discrimination Act 1992* (Cth), there need to be strategies that are aligned with contemporary understandings of disability discrimination reflected in the Convention.
- That is, mainstream services need to be supported to not just prevent and address discrimination but to actively identify and make ‘reasonable adjustments’ to make their services accessible.
- For example, in the United Kingdom under the National Health Service, a number of resources are available to health staff to improve their responsiveness to people with learning disabilities and improve the accessibility of their services including a ‘health passport that contains important information about the person including their medical history, likes and dislikes, how they like to communicate etc. (<http://www.gmc-uk.org/learningdisabilities/333.aspx>)
- This work is resource-intensive, requires coordination and would need to be underpinned by a clear mandate.
- While local innovation should be encouraged, it needs to be supplemented by legislation, policy and programs.

### Important Questions:

- How will best practice be identified and evaluated, and how will outcomes be measured?
- How will systems be set up to proactively identify infrastructure and/or servicing issues that have the potential to inadvertently discriminate against people with disability?
- Who will take overall responsibility for ensuring mainstream services are responsive and make reasonable adjustments for people with disability?

### Stream three: Community awareness and capacity building

- Of crucial importance is the need to build inclusive communities to create opportunities for people with disability for social and economic participation.
- The strategies identified in the ILC Framework in stream three such as public campaigns, training, community activities and investing in product design and technology are important.
- Other important strategies include urban design (including transport and planning), as well as accessible and appropriate housing.

#### Important Questions:

- Where strategies sit outside the mandate of the NDIS, who will take responsibility for ensuring that such strategies are prioritised and pursued?
- How will the overall programmatic agenda be set, funded and communicated?
- How will the learnings from different communities be used to inform the promotion of best practice standards for accessible and inclusive communities?
- What are the necessary legislative, policy and infrastructure requirements to enable the necessary outcomes to be achieved?

### Stream four: Individual capacity building

- Strategies for individual capacity building must also include specific strategies for people with impaired decision-making capacity, as well as making reasonable accommodation for people with intellectual and cognitive impairments.
- Some of the strategies identified such as training courses, peer support groups etc could be carried out through the infrastructure of neighbourhood and community centres, not just specialist disability services.
- Such strategies would also assist in creating inclusive communities and reducing the isolation and segregation of people with disability.
- This will require state governments to maintain investment in these initiatives, and may also require a legislative mandate to ensure strategies are appropriately prioritised and actioned.

#### Important Questions:

- How is the NDIS taking into account the specific needs of people with impaired decision-making capacity and contemporary research into supported decision-making in its consideration of the services that will be provided in the *Individual capacity building service* stream?

## Stream five: Local area coordination (LAC)

- Local area coordinators will have a crucial role under the ILC Framework and must be well resourced and sufficiently skilled. Under the current system, a lot of innovation occurs as a result of locally coordinated responses. However these initiatives are inevitably frustrated in their attempts to achieve outcomes at the level to which they would ideally like, from both the individual and systems perspectives, as a result of a lack of support from the necessary levels of Government. This often occurs as a result of systems at that level continuing to operate in silos and without the flexibility required to be coordinated and responsive at a local level.
- This again begs the question about the infrastructure at a policy and programmatic level that will support local area coordinators to carry out their role. It will be important to ensure that local area coordinators have sufficient authority and influence to direct the necessary community responses, and that all levels of Government support such initiatives accordingly.

### Important Questions:

- How will the NDIS ensure appropriate commitment is obtained from state/territory governments to assist the *Local area coordination* service stream by ensuring appropriate resourcing of and support for local initiatives?
- What community infrastructure might be required to support local area coordination and how might this service stream be positioned to navigate existing service systems and mitigate against duplication of resourcing if necessary?

## Implementation and Funding Principles

- The funding principles place an emphasis on outcome-based funding, where outcomes are achieved transparently and efficiently. One of the important lessons that has been learnt from other insurance-based schemes is that it is important to measure outcomes and efficiencies over the long-term. For example insurance-based schemes for people with Acquired Brain Injury have found that early interventions may be resource intensive at the start (eg intensive rehabilitation) but over the long term reduce the cost of the person's overall life-time support needs and have better outcomes for the person.
- The ongoing role of philanthropy and volunteers and a suggestion that the NDIA should encourage and strengthen the involvement of this sector is an important principle for implementation of the ILC Framework. Some of the issues that impact the ability of agencies and organisations to engage volunteers include the resourcing associated with systems and processes such as WHS, criminal history screening, blue cards, yellow cards, etc. The potential to streamline these processes may be worthy of consideration, although the need for appropriate safeguards is an important factor in any such review processes.

### Important Questions:

- How will the funding principles recognise the lessons from other insurance-based schemes, which are particularly relevant to people with acquired disabilities and children with disability?
- Who would take responsibility for evaluating systems and process such as WHS, criminal history screening, blue card, yellow card, etc that may currently inhibit the willingness and ability of service organisations to engage volunteers?



## Concluding comments

Thank-you for the opportunity to provide feedback on the *National Disability Insurance Scheme Framework for Information, Linkages and Capacity Building*.

I am pleased to see that the importance of taking a multi-faceted approach to ensuring the responsiveness of local communities and enhancing supports for people with disability is being appropriately acknowledged and considered in the progressive development of the National Disability Insurance Scheme.

I trust that the comments that I have provided are useful in contributing to a more fulsome consideration of the complementary activities that may be required by the state/territory and Commonwealth governments in ensuring that the implementation of the ILC Framework achieves optimal success.

I look forward to ongoing discussions about the ILC Framework in the interests of supporting its successful implementation, and promoting effective and sustainable outcomes for people with disability accordingly.



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