A Framework for Information, Linkages and Capacity Building

Overview

This paper sets out policy parameters for Information, Linkages and Capacity Building (ILC), formerly known as Tier 2, in the National Disability Insurance Scheme (NDIS). This policy framework will provide guidance to the National Disability Insurance Agency (NDIA) in developing a transition and implementation strategy for ILC. The Disability Reform Council have agreed to replace the term Tier 2 with "ILC". The term ILC provides more clarity regarding its purpose and removes the potential for misinterpreting the NDIS as a hierarchy of supports, which was implied by references to 'tiers'.

The term recognises that ILC should be broadly scoped, flexible and responsive to the support needs of people with disability, their families and carers. A broad definition will ensure that those supports can evolve over time to meet those needs. ILC is a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and carers which in turn will reduce the need for funding of supports for people with disability through Individual Funded Packages.

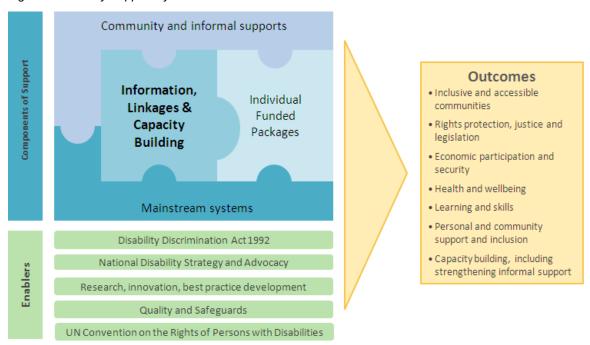
Purpose of Information, Linkages and Capacity Building (ILC)

People with disability engage both directly and indirectly with a range of informal and formal supports and resources over their lifetime, to assist them with their everyday needs and their social and economic participation. Their engagement is influenced by a range of societal, environmental, demographic and disability-specific factors such as: age; location; socioeconomic and cultural background; type and severity of disability; cyclical or episodic nature of disability; and capacity of the community to accommodate diversity and reduce the impact of disability.

A social insurance model invests in formal, disability-specific support to reduce the lifetime cost of disability, at both the population level and individual level. Investment in community education, broad-based interventions and capacity building sustains and strengthens informal support and promotes the social and economic inclusion of people with disability. A system that responds only to an individual's need is not enough to ensure societal change.

ILC will allow the NDIS to influence and shape the delivery of supports at a systemic level to provide better outcomes for people with disability, their families and carers. Over time, this can reduce the demand for, and level of support required through individually funded responses (and thereby reduces long-term scheme costs). ILC enables the NDIS to fund supports not directly tied to an individual and, by doing so, gives the scheme the ability to deliver its operational and strategic objectives. The below diagram illustrates the role of ILC in the context of other elements of policies and programmes to support people with disability. This includes the core components of support and service delivery (blue blocks), as well as the enablers that influence the delivery of the above components (green blocks).

Figure 1: Disability Support System



This diagram illustrates that 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. ILC has the capacity to:

 strengthen mainstream service and community capacity to be inclusive of people with disability

Not all elements of the life of a person with disability should be delivered through individual funded supports - nor is it economically feasible to do so. Mainstream services and supports, which all Australians rely on, have a responsibility to provide for people with disability. This includes access to healthcare, education, transport and housing. Information, referral and linkages ILC functions should assist in facilitating referral to and from mainstream service systems for people with disability.

ILC encompasses capacity building across communities, organisations, and mainstream service delivery, to influence attitudes and practices that can lead to greater inclusion and engagement of people with disability, as well as delivery of support that suits the needs of people with disability their families and carers.

This approach, consistent with effort under the National Disability Strategy 2010-2020, is very important in improving outcomes for people with disability and will also assist in reducing the demand for, and the cost of, disability-specific services.

foster continual improvement and innovation in disability support delivery

The NDIS, through ILC, can improve the quality of practice and support delivery as well as promote innovation, leading to improved organisational and personal outcomes and enhanced scheme outcomes.

Access to ILC will achieve the following system benefits and efficiencies.

- people with disability, their families and carers can access supports consistently across jurisdictions, minimising the risk of the development of multiple service systems.
- as time goes on, the delivery of ILC supports will become more efficient and cost
 effective, due to the development of stronger informal support networks, increased
 community capacity, better mainstream responses to disability and the focus on
 preventative supports for people with disability.
- stronger local support networks the delivery of ILC supports will adapt to the local context, complementing and building on existing disability, mainstream and informal support and service networks.
- expanded gateway to various service systems links between other service systems (for example, healthcare, aged care, education) will improve to support the varying needs of people with disability, their families and carers.
- minimise the need for escalation of support into an IFP through early intervention, prevention and capacity building, including to sustain the support provided by carers.

The delivery of disability specific non-individualised supports to people with a disability who would otherwise seek or require an IFP, will contribute to the efficient implementation of the NDIS.

The NDIS will focus on providing supports at significant life stages and transition points, to build capacity and enable people with disability to participate in economic and social life, and sustain carers in their support role. Early intervention and prevention supports may be accessed either through an IFP or through ILC supports, depending on the nature of the support and the person's overall support needs. This aspect of the NDIS will enable individuals with less intensive support needs to receive that support outside an IFP.

Access to ILC

The focus of ILC is not on who will access it, but on the supports offered.

The NDIS Scheme Actuary advises that of Australia's population of people with disability, there are approximately:

- 2.5 million under the age of 65 years
- 900,000 of the 2.5 million report they need assistance with activities of daily living at least weekly
- 410,000 of this 900,000 are likely to access the NDIS as participants

Of the 800,000 carers identified by the Productivity Commission, approximately:

- 394,000 are carers for people under 65 years of age
- 350,000 of these 394,000 carers are supporting a person under the age of 65 years with either a severe or profound core activity limitation.

People with disability (including those who also receive an IFP), their families and carers can benefit from ILC supports. Some aspects of ILC (such as Information, Linkages and Referals

and Community Capacity Building) will benefit a wide group of people with disability, their families and carers. Mainstream and community services will also engage with ILC supports through streams which are targetted towards building a more inclusive and supportive community for people with disability, their families and carers. Other supports (particularly Local Area Coordination and Individual Capacity Building funded in the NDIS) will benefit people:

- who need support so that their capacity to live independently does not deteriorate to a point where they would meet the access criteria for the NDIS and require an IFP to participate socially or economically in the community; or
- who would otherwise meet the access criteria for the NDIS and would therefore be eligible for an IFP, but only require low levels of support that could be provided through ILC;
- who access specialist supports through an IFP but also have needs that can (and should) be supported through the mainstream or community sectors, and/or ILC; or
- who need low levels of support to live independently in the community, but are not eligible for an IFP, where access to ILC will prevent them having to test their eligibility for an IFP;

Local Area Coordination and individual capacity building supports will also provide support for carers to sustain their role.

People with disability who are over the age of 65 years, will access information and referral or benefit from community capacity building; however, they will likely gain most of their supports from the aged care system. The NDIS and aged care interface arrangements should be complementary.

Given the large variation in the impact of disability on the 2.5 million people, a significant proportion is likely to receive most, if not all, the supports they need through mainstream systems.

Five Streams

There are five streams of service under ILC which provide support to people with disability, their families and carers, and community and mainstream services. The streams are:

- 1. Information, Linkages and Referrals
- 2. Capacity building for mainstream services
- 3. Community awareness and capacity building
- 4. Individual capacity building
- 5. Local area co-ordination (LAC)

Examples of activities under the five streams are explored below. Whilst the streams are considered separately in this document, they could be implemented with consideration to a variety of service delivery models, including multi-stream combinations.

Stream one: Information, linkages and referrals.

Information, linkages and referrals will efficiently connect people with disability, their families and carers with appropriate disability, community and mainstream supports.

Information is usually needed before people are able to access services and supports. The types of information that people with disability, their families and carers, may seek to access include:

- information about specific disabilities and the impacts of diagnosis
- information about supports targeted for people with disability, their family and carers, as well as generic community-based supports
- information on specific disabilities that aims to assist people with disability, as well as their families and carers, to best use available supports to promote independence and enhance the capacity to self-navigate service systems
- support to use existing information sources or relevant organisations to access and acquire information
- information that addresses the needs of culturally and linguistically diverse communities through the context of location and background
- information that addresses the needs of Indigenous Australians and their respective language, social or nation groups

It is also intended that people with disability, their families or carers will use the information and referrals function as a gateway to the NDIS – a range of community, mainstream and private organisations can also refer people to access NDIS supports. This function will also support the development of information networks which will help people navigate the range of supports available as part of the NDIS.

For this reason, a variety of resources could be made available to the public, including information online and through face-to-face services. A centralised electronic database of providers could be developed that indicates the range of products and services, their availability and links to measures of performance and quality.

This role may be outsourced, with organisations funded to provide these services. Additionally, funding organisations to provide information and referral services will ensure that people who do not have a relationship with the NDIS can continue to access these services. It will also enable the NDIS to utilise and support established networks.

The NDIS could encourage informal supports in the provision of information and linkages to people with disability. Families, carers and peers are a valuable network of knowledge and can provide connection to a variety of services.

The NDIS could assist people to access services and supports, as part of the NDIS pathways to support function. This could potentially be incorporated into the Local Area Coordination role. All of these services would be delivered using formats that are accessible for all people with disability.

Initiatives under this stream could include:

- web-based supports
- telephone information
- face-to-face information supports
- group infomation sessions
- encouraging peer support and information sharing

- fact sheets
- pre-planning support
- referral and linkages to other supports.

This support may be delivered through disability-specific organisations and programs, or through whole of population programmes where ILC will aim to ensure that the programme is adapted to be inclusive or particularly responsive to people with disability (e.g. parenting programmes may be provided that include sessions specific to parenting a child with disability).

NDIS should encourage the continued operation of these organisations and activities, and may contribute funding recognising the broad community benefit and specific early intervention outcomes achieved.

Stream two: Capacity building for mainstream services.

People with disability, their families and carers, like all community members, access and interact with mainstream and universal systems and supports. NDIS will fund supports to enhance social and economic participation for people with disability, but it is not a funding source for mainstream services.

Mainstream services are considered to be government funded services (for example, education, health care, public housing, transport and employment services), and services/supports provided by the community or private sector (for example, a swimming pool, neighbourhood houses and men's sheds, gym or theatre).

An NDIS objective is to ensure people with disability connect with and access mainstream supports. 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.

Importantly, the NDIS will be able to identify areas for improvement at the local level and develop in collaboration with key partners specific strategies, such as:

- building the capacity of mainstream and universal providers
- enhancing their inclusiveness of people with disability
- providing organisations with information on how to improve their accessibility
- enhancing 'best practice' in service delivery.

Stream three: Community awareness and capacity building.

Investing in community awareness and capacity building will create opportunities for the social and economic participation of people with disability, their families and carers, improving personal outcomes and strengthening the connection between people with disability and their communities.

An objective of community capacity building is getting organisations (not for profit organisations, local councils, businesses) and people within communities to be inclusive of people with disability, and understanding of the needs of families and carers.

The NDIS recognises that governments play a role in fostering the social inclusion of people with disability and their families and carers and that these activities should continue and complement the NDIS.

The NDIS has a key role in supporting and strengthening effective local initiatives by community groups and businesses to address disability issues in the community (e.g. social isolation). This may include the provision of funding.

Initiatives under this stream may include:

- Public campaigns to improve the community's general disability awareness and understanding.
- Creating personal networks that connect people with disability to opportunities (e.g. employment opportunities) they may otherwise miss.
- Basic training to individuals (e.g. paid employees, business operators or volunteers) to enable them to more effectively relate to, or work with, people with disability.
- Community activities in which people with disability can participate.
- Consulting with, or incorporating the views of, people with disability, their families and carers in the provision of community activities and other goods and services.
- Investing in product design and technology to actively facilitate the inclusion of people with disability in the community.

It is intended that this Stream will support the insurance principles of the NDIS, reducing the burden on disability supports by building the long-term capacity of the community to more effectively support people with disability, their families and carers. Activities undertaken within this Stream should demonstrate consideration of this.

Stream four: Individual capacity building

Individual capacity building fosters the principle of choice and control, improving outcomes for people with disability, their families and carers as well as driving market changes, including potential cost reductions, through innovation as participants' needs and expectations evolve.

These supports are often one-off, low level or episodic and are better delivered and managed through funding arrangements other than through individual plans.

Individual capacity building has the potential to benefit a range of people with disability, and their families and carers, who are eligible for IFP or who are just outside of the access criteria for the scheme and would otherwise need to test their eligibility (and therefore support the insurance principles of the NDIS). This funding stream can support courses, groups and organisations to help build capacity; facilitate mentoring and peer support; and help provide people with information to support choice.

Examples of supports may include:

- Diagnosis-specific capacity building (e.g. orientation training for people with vision impairment where this is low cost and short term);
- Programmes for carers and counselling for people who are caring for someone with disability or mental illness;
- Parent breaks and programmes to provide parents with skills and information about disability;
- Professional development e.g. for parents and education providers;
- Diagnosis specific peer support groups.

These can be effective in supporting an individual with planning, establishing linkages with mainstream and other supports, facilitating peer support networks and understanding the most effective support options appropriate to the individual's specific disability.

To build the capacity of people with disability, the NDIS could:

- Fund and facilitate local support networks to provide opportunities for people with disability to learn from the experience of others;
- Fund peer support groups to lessen isolation e.g. for people with a mental illness or an acquired brain injury;
- Fund training courses and mentor programmes to help people to self-advocate and assume increasing levels of choice and control over funding, supports and interactions with providers;
- Fund and facilitate carer capacity building and support programs; and
- Provide one-off, low level or episodic supports which focus on preventative intervention e.g. counselling.

This support may be delivered through disability-specific organisations and programs, or through whole of population programmes where ILC will aim to ensure that the programme is adapted to be inclusive or particularly responsive to people with disability (e.g. parenting programmes may be provided that include sessions specific to parenting a child with disability).

The NDIS should encourage the continued operation of these organisations and activities, and may contribute funding recognising both the broad community benefit and the benefits to individuals, families and carers.

Stream five: Local area co-ordination (LAC)

LAC is the development of relationships between the NDIS, people with disability, their families and carers, and the local community (including informal networks, community groups, disability and mainstream services).

LAC will ensure that people with disability, their families and carers, are able to make full use of the mainstream and other services (including diagnostic-specific information) available to them. LAC will also help to streamline their NDIS experience and assist them to navigate the variety of NDIS supports. At times, LAC support to link with other informal supports or service systems may be the only support that a person or their carer needs.

LAC will also promote community inclusion and provide strong visibility of the local disability support system. For the NDIS, this visibility will contribute to the streamlined and efficient delivery of supports and ensure connected responses to support by complementing the existing services of the local community.

The role of the LAC can incorporate:

- Active involvement in building the capacity of other community services to respond to the needs of people with disability and carers and to develop natural networks of support around people with disability;
- Prevention, capacity building and locally based practical solutions which are fundamental to ILC and the concept of a wide entry gateway;

- Building and supporting informal support systems;
- Formal services and funding as the last, not the first, response. This role is delivered through:
 - working with people with disability, their families and carers to consider their immediate and future goals and how these might be best achieved.
 - working with individuals and their families to achieve their goals by building new networks and accessing support and services in their community.
 - working alongside communities and mainstream services, supporting them to become more welcoming and inclusive;
- Access to a small amount of funds to enable purchase of one-off supports or to seed fund community capacity building, community inclusion activities or individual capacity building.

It should be noted that LAC functions could be undertaken by an individual or a small team, depending on the needs of people with disability, the community and the local context. All people with disability will benefit from the community building and mainstream support roles of the LAC, and the level of intensity of LAC involvement will be greater for Scheme participants with a lighter touch for the broader population.

Implementation principles and considerations

Context

All jurisdictions have agreed on the Framework for ILC supports under the NDIS. The Framework has been developed to guide the NDIA's implementation and operationalisation of ILC supports, in line with the agreed implementation and funding principles. *Implementation Principles*

Purpose of ILC Supports:

- ILC supports have a focus on capacity building for people with disability; their families and carers; communities; mainstream support sectors and organisations.
- ILC supports enable and strengthen the economic and social participation of people with disability in their communities.
- ILC and IFPs are not mutually exclusive. ILC supports are available to people with disability, their families and carers, regardless of whether they are receiving an IFP.
 ILC supports may be the only interaction a person requires with the NDIS or may complement a participant's IFP.
- Implementation of ILC and IFP establishes a range of support approaches which people
 with disability can utilise. This ensures that people requiring only low-level specialist
 disability supports can access the support they require without the need for intensive
 eligibility or planning processes.

Structure and Implementation of ILC:

• The ILC Framework must provide flexibility to enable the NDIA and each jurisdiction to implement the agreed ILC policy in line with the individual jurisdictions' transition models.

- ILC supports should be planned and implemented in collaboration with existing and continuing service arrangements, recognising the role of local and jurisdictional planning, governance and consultative structures.
- Configuration of 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.
- ILC supports should not inhibit philanthropy and volunteers. The NDIA should encourage and strengthen involvement of this sector.

Range of Supports and Approaches:

- ILC enables pathways, supports and services across each successive life stage.
- ILC supports have regard to differences in current jurisdictional operations.
- ILC supports are highly flexible and evolve over time, in line with changing needs (either locally or nationally) and based on good practice and ongoing learning.
- ILC supports are responsive to the needs of people with or affected by disability, their families and carers.
- ILC promotes peer support and facilitates the contribution of lived experience of disability, as a means of capacity building for individuals, mainstream systems and communities.
- ILC has the capacity to deliver supports for the dual purposes of early intervention (avoiding escalation of the impact a person's disability on their functional capacity) and scheme sustainability (cost implications of providing all supports through individualised arrangements).
- ILC supports operate under the quality and safeguard principles implemented in the NDIS.
- The NDIS should have capacity to provide ease of access to one off low cost supports or low cost equipment where it is sufficient to facilitate independent living or social and economic participation, or reduce potential future support costs and requirements. For some people with disability, a one off or low cost piece of equipment could mean the difference between requiring ongoing funded support and the ability to continue an independent life. This may include the purchase of low cost items such as a communicator, household equipment, or specialist training such as orientation or travel training where this is short term and low cost.

Interfaces:

- ILC supports align with, and may assist in the realisation of, jurisdictions' responsibilities under the National Disability Strategy.
- All jurisdictions have agreed (through COAG) on principles to guide the interface between the NDIS and mainstream support sectors. ILC supports may assist jurisdictions and mainstream sectors to meet their agreed responsibilities, but will not replace mainstream support delivery for people with disability.

Intersection with Individual Funded Packages

The ILC and IFP functions of the NDIS overlap, with a person able to receive supports through either function or from both functions. A person may access support through ILC without receiving an IFP; for example by making an enquiry that results in a referral to another service system. Alternatively, a person may receive support through both functions e.g. accessing a combination of specialist disability supports, LAC support and support through the mental health system.

IFP will fund reasonable and necessary supports that cannot be sourced through informal, community or mainstream networks. Options under ILC should ensure that ILC supports are easily available without the need to complete formal planning processes through the NDIA. People who have an IFP can also access supports available under ILC.

The range of activities offered under ILC should minimise the need for people to receive support that is individually funded under the NDIS. Through individual capacity building, people with disability, their families and carers may also receive the support that stabilises their needs, and helps to slow or prevent its escalation to a level that requires an IFP. This is a key component of the NDIS social insurance model and will contribute to the sustainability of the NDIS.

For people who aren't receiving an IFP, supports provided under ILC will assist them to live independent and active lives, with a focus on preventative intervention. For example:

- ILC can provide one-off, low-level or episodic supports, minimising the likelihood of a
 person becoming eligible for an IFP in the future. Further work is necessary to
 establish a decision-making framework for these cases.
- A person may meet the access criteria for the NDIS and therefore be eligible for an IFP, but can choose to access one-off or low-level or episodic support through ILC instead. In determining access to these supports, the NDIS should consider whether more extensive and immediate support is necessary (and therefore require the development of an IFP) and the extent to which the general disability supports under ILC will be sufficient preventative intervention.

Intersection with mainstream sectors

Mainstream sectors have a responsibility to address structures and systems that are barriers to access, including responsibility to put in place adaptations that meet the needs of people with disability. It is important that the NDIS not become responsible for supports that are not within its scope. In ensuring equitable access to universal services, mainstream systems may include supports accessible to people with disability in general e.g. special schools, support classes, or support targeting people with particular disability e.g. specialist diagnostic clinics.

It is important that all governments maintain their effort with respect to the implementation of the National Disability Strategy 2010-20. The Strategy was agreed by all Australian governments in February 2011 and provides the framework for disability reform in Australia. While improvements in the provision of disability specific supports, such as the NDIS, are an important component, the Strategy has a particular focus on improving the performance of mainstream service systems to ensure that people with disability have equal access. Governments agreed on six key policy areas which were based on consultation with people with disability:

Inclusive and accessible communities

- Rights, protection, justice and legislation
- Economic security
- · Personal and community support
- Learning and skills
- · Health and wellbeing

Likewise, under the Commonwealth *Disability Discrimination Act 1992* and other relevant State and Territory laws, mainstream supports and services are required to ensure that goods, services and facilities do not discriminate against a person because of their disability.

These responsibilities will not change with the roll out of the NDIS.

Funding Principles

ILC supports can be funded through a range of mechanisms, provided they are outcomesbased and encourage the development of a competitive and innovative market, that allow the NDIS to target its funding to achieve intended outcomes transparently and efficiently.

The ability to choose an appropriate funding mechanism allows the scheme to target funding carefully to respond to systemic issues that impact on outcomes for participants, non-participants, support sectors and the scheme.

ILC funds supports, determined as necessary by the scheme, are not funded through a person's IFP, but are instead funded by the scheme, either through its own internal operations or by directing funding to a third party, such as a service provider.

ILC supports can be funded through a range of mechanisms. Funding may, depending on the support and its intended purpose, be provided through:

- Bulk purchasing arrangements;
- A contract for support;
- Grants for short-term capacity building programs or building works to improve community accessibility; or
- Staff employed by the NDIS to deliver a particular service e.g. planners, assessors;
 or
- Local Area Coordinators with access to a small amount of funds to enable purchase
 of one-off low cost supports (such as small items of equipment or individual capacity
 building), and to seed fund community capacity building and community inclusion
 activities. This can enable the NDIS to ensure that people who have very low cost
 support needs and do not require a long term relationship with the NDIA through an
 individual plan can receive once off support that prevents them having to apply to be
 a participant without theneed for intensive eligibility and planning processes.

These funding mechanisms should have accountability measures that are linked to outcomes, such as supporting people with disability to exercise choice and control and navigate systems; sustaining families and carers in their caring roles; improving access to the community and mainstream services; and increasing the evidence base on effective early intervention and prevention. Guidelines would need to be developed to support and target decision making by LACs on use of funds for one off low cost supports (such as low

cost items of equipment, or individual capacity building) and community capacity building and inclusion activities.

Social capital, provided predominantly through philanthropy and volunteers, is intrumental in increasing the capacity of organisations to deliver supports to people with disability, their families and carers. The NDIS should encourage social capital and activities under ILC should facilitate its involvement, where appropriate.

A competitive and innovative market for ILC can be fostered through:

- A variety of procurement processes, for example seed funding organisations to harness social capital and philanthropy
- Local Area Coordinators having access to a small amount of funds to enable
 purchase of one-off supports or to seed fund community capacity building,
 community inclusion activities or individual capacity building. These funds could
 establish a culture of small-scale innovation and experimentation by providing ease
 of access to supports or equipment that people with disability suggest or nominate as
 having the potential to reduce future support costs and requirements.

All funding should be subject to review mechanisms that enable demonstration of benefit to scheme objectives.