

NSW DISABILITY NETWORK FORUM

Introduction

The NSW Disability Network Forum (DNF) thanks the National Disability Insurance Agency (NDIA) for the opportunity to provide a response to the discussion paper on the Information, Linkages and Capacity Building (ILC) Policy Framework.

About the NSW Disability Network Forum

Initiated in June 2011, the NSW Disability Network Forum comprises non-government, non-provider peak representative, advocacy and information groups whose primary aim is to promote the interests of people with disability. The aim of the NSW Disability Network Forum (DNF) is to build capacity within and across all organisations and groups so that the interests of people with disability are advanced through policy and systemic advocacy. The Council of Social Service of NSW (NCOSS) provides secretariat support to the DNF.

NSW Disability Network Forum Member Organisations:

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| Aboriginal Disability Network NSW | Multicultural Disability Advocacy Association of NSW |
| Association of Blind Citizens of NSW | NSW Consumer Advisory Group - Mental Health |
| Brain Injury Association NSW | NSW Council for Intellectual Disability |
| Deaf Australia NSW | NSW Disability Advocacy Network |
| Deaf Society of NSW | People with Disability Australia |
| DeafBlind Association NSW | Physical Disability Council of NSW |
| Deafness Council (NSW) | Positive Life NSW |
| Information on Disability and Education Awareness Services (IDEAS) NSW | Self Advocacy Sydney |
| Institute For Family Advocacy | Side By Side Advocacy Incorporated |
| Intellectual Disability Rights Service | Council of Social Service of NSW |

Overview

The DNF welcomes this discussion paper as recognition by the NDIA that building the capacity of the community to support and promote inclusion is crucial to the success of the NDIS. The ILC Policy Framework aligns with the New South Wales Government's commitments in the recently released Disability Inclusion Plan, particularly in relation to the outcomes of:

- developing positive community attitudes and behaviours
- creating liveable communities
- improving access to mainstream services through better systems and processes

Additionally, investment in ILC supports is cost-effective, reducing the reliance of some people with disability on Individual Support Packages (ISPs).

The DNF emphasises the importance of maintaining a skilled and informed sector in order to deliver on the ILC Policy Framework. Additionally, the DNF argues that the Policy Framework would be strengthened by being outcomes based, and focusing on the needs of local communities, including those based on geographic location, cultural group and disability type.

Uncertainty for organisations already providing ILC type services

The members of the DNF note that their work and functions cover many of the 'streams' of ILC outlined in the discussion paper. Through their focus on individual and self advocacy and advocacy

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for family members, DNF members assist people with disability and family members to build capacity, refer them to the organisations that can assist them, provide them with information and support them to have their rights respected. For example, many organisations provide information and advocacy services, fitting directly within Streams 1 and 4. Through many years of experience, DNF members have built extensive networks and deep collaborations with people with disability and their families, and a knowledge base that can't easily be replicated. DNF members report that they often provide the important 'link' between the person with disability and government or service provider. Many organisations within the DNF also work with people with disability in their local environment.

The DNF is concerned that the capacity of the sector to deliver ILC services may be diminished by the time the framework is implemented. Many of the members of the DNF have no guarantee of funding beyond June 2016. This has resulted, in staff being given short term contracts, being made redundant or leaving the sector—trends which will continue until certainty of funding is provided. Crucially, these trends will decrease the skills available to deliver ILC services, while people with disability will feel uncertain if known and trusted sources of support (both individual and organisational) are no longer available.

Much of the work of DNF members is systemic advocacy, which is driven and informed by the cumulative knowledge derived from advocating for individuals and families. While the DNF is aware that the Quality and Safeguards Framework has just been released, and understands that systemic advocacy will be discussed at the Council of Australian Governments meeting in April 2015, there is uncertainty among members regarding how these policies and frameworks will intersect. This uncertainty makes it difficult for stakeholders to understand, critique and effectively contribute to the policy framework within which they may be operating. It is particularly difficult to identify 'gaps' in the overall framework.

The DNF believes people with disability in NSW must have uninterrupted access to services such as information provision and individual advocacy. A known timeline for ILC implementation will allow an assessment of whether this continuity will occur. Additionally, clarity around the timing of ILC implementation will assist NSW organisations that have the skill-base, networks and trust of their communities to plan for a future beyond 2016.

Recommendation 1

That a timeline outlining ILC implementation milestones be released as soon as possible to ensure;

- continuity of services for people with disability in NSW;
- maintenance of the capacity of the sector to deliver quality services related to the ILC framework.

Recommendation 2

That a document outlining the intersection between the ILC, quality and safeguards and systemic advocacy policy frameworks be developed as part of the next consultation phase to allow gaps in the overall system to be identified and addressed.

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Comments on the elements of the ILC Policy Framework

The DNF makes the following comments on the five streams of the ILC Policy Framework outlined in the discussion paper, while recognising the streams are fundamentally interlinked:

1. Information, Linkages and Referrals

Information services provided by DNF members are proactive as well as reactive. Presently, information officers add value to the provision of information by seeking, researching, analysing, promoting information, producing resources and keeping abreast of trends, policy developments, reforms and issues in the media, in order to be able to provide contextually relevant and responsive service. Information services can employ targeted communication strategies that make information accessible to all and suit the communication requirements of every person with disability

The DNF highlights that it is crucial that the information and referrals provided within Stream 1 be independent of service provision, to ensure impartiality. To ensure accessibility, the information should be provided in a variety of community languages and formats, including easy English and Braille. DNF members emphasise that in order for generalist information to be effective, specific information relevant to particular disability groups also needs to be available.

While supporting the social media and other technologies outlined in the discussion paper, the DNF believes it is critical that these methods supplement, rather than replace, the face-to-face and telephone communication many DNF members are able to facilitate between people with disability. These methods are valued because they allow responses to be tailored to each individual, in contrast to a 'one-size fits all' approach. People with disability have mixed levels of literacy and skills with technology, and programs such as *My Choice Matters: New South Wales Consumer Development Fund* have had success engaging people with disability through media including DVDs and peer stories, featuring role models with which people with disability can relate.

Recommendation 3

That general and specific information services be funded to provide information in a range of forms and formats to suit the communication needs of all people with disability.

Recommendation 4

That information, linkages and referral services funded under Stream 1 are independent of organisations that provide direct services to people with disability.

2. Capacity building for mainstream services

The DNF believes that initiatives in Stream 2 should draw on the experience of people with disability, consulting them about their views of mainstream services and using their feedback to make services more accessible, user-friendly and responsive to people with disability. Services need to be working in an empowering and inclusive approach, for example, assisting people with disability to join existing programs and services by making them more inclusive, rather than establishing separate 'specialist' services (eg drama class for people with disability).

As will be explored below, outreach is critical for people on the fringe of society, who may not currently engage with disability supports, due to factors including geographic and/or cultural isolation, or a low level of impairment. Mainstream services dealing with vulnerable people,

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including legal and Court services, need to be resourced with accurate information so they can assist in engaging these people with the NDIS.

The DNF urges the NDIA to investigate ways to promote success stories arising within Stream 2, which would encourage and magnify similar responses across the community. Similarly, reporting of challenges will assist in identifying areas that require systemic change —allowing policy responses to be targeted and evidence-based.

Recommendation 5

That mainstream services be trained and resourced to provide outreach to clients who may have a disability—including those who have traditionally been isolated through a lack of service provision, location or disability type.

Recommendation 6

That a mechanism be established to share the learnings of Stream 2 across the community.

3. Community awareness and capacity building

The DNF welcomes the inclusion of this Stream, but would like to clarify around its aims and messaging. It is important that public campaigns funded within Stream 3 should ensure people with disability are not stereotyped, emphasising that individuals who may be profiled do not represent all people with disability. Marketing of this stream should highlight the benefits of inclusion to the wider community, not just people with disability or the NDIS.

Additionally, the DNF highlights that many of its members provide training to people with disability and service providers, which fits within Streams 3 and 4. It is our view that this experience should be harnessed in Streams 3 and 4 to maximise opportunities for people with disability and reduce duplication and implementation costs.

Recommendation 7

That initiatives funded in Stream 3 harness existing knowledge to promote the benefits of inclusion to the wider community.

4. Individual capacity building

The DNF stresses that, as with Stream 1, capacity building initiatives in Stream 4 should be independent of service provision, to give people with disability the skills to choose between services and support. A crucial first step to building capacity is ensuring people with disability have their communication needs met, without which choice and control cannot be realised. Likewise, strengthening the natural supports around people with disability, and training in self-advocacy, are important precursors to individual capacity building.

The DNF encourages the NDIA to investigate how this and other ILC streams will work to assist people with disability who have not traditionally had the benefit of services that respond to their particular needs. For example, young people in aged care and people in the deaf-blind community have not traditionally had good access to services and people who are leaving institutional care may have very low experience in exercising choice and control. The DNF suggests that targeted funding to assist people in these communities should be made available. This will ensure that the NDIS encourages real change and does not continue to produce less than perfect outcomes for people with complex and/or presently unmet needs.

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The comments of the DNF in relation to Stream 5 (Local Area Co-ordination) are outlined below. Additionally, as explored below, the DNF emphasises the importance of delivering the entire ILC Policy Framework in a culturally appropriate manner.

Recommendation 8

That specific capacity building be provided to assist people with disability who have not traditionally had the benefit of services that respond to their particular needs

Greater focus on outcomes

The DNF observes that the discussion paper is pitched at a high level, and emphasises that more detail of the ILC Policy Framework is needed. The paper presents 'inputs' of five funding streams and discusses systemic outcomes. The DNF believes greater focus on the outcomes achieved for people with disability would strengthen the framework.

Outcomes are more likely to be achieved if the 'streams' of ILC are conceptualised flexibly, enabling services to focus on meeting the specific needs of the individual with disability. The DNF members emphasise that the services they provide fit within many of the 'streams' outlined in the discussion paper. For example, seminars provide information while building the capacity of the individual and the community.

In relation to Stream 2, capacity building for mainstream services, the DNF stresses that the system needs to provide incentives for the mainstream to include people with disability. As explored below, the outcomes achieved must be culturally responsive, as part of ensuring truly person centred supports. One way of encouraging the achievement of outcomes within the streams of ILC is to involve people with disability in the design of the framework, and to employ people with disability in service provision roles.

Recommendation 9

That contracts for services funded within the ILC Policy Framework be drafted flexibly, enabling organisations to be responsive to need, rather than being constrained by particular 'deliverables'.

Recommendation 10

That services funded within the 5 streams outlined in the discussion paper need to identify:

- outcomes to be achieved for people disability;
- how they are co-designed with people with disability;
- how they address are culturally responsiveness;-
- how people with disability benefit from all areas of employment created.

ILC services need to be appropriate to local communities

The DNF believes there are three separate facets of 'local' community to which the ILC framework must be responsive – disability type, cultural group and geographic location. These facets will be addressed in turn:

Geographical location

The DNF understands the discussion paper explains the ILC Policy Framework at a high level. It would also be useful to understand how this framework will increase access to services for people in remote, rural and regional areas. The DNF believes outreach and relationship building will be very

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important in rural and remote communities. People with disability from rural and remote areas are often isolated, experiencing far less choice and control in relation to services. For example, DNF members report that they are aware of people with disability from rural and remote areas who have disengaged from the "Ability Links" program in NSW because of the high cost of mobile phone calls to the Ability Linker who did not travel to the consumer's local area. Telephone advice and information services are particularly important means of connecting with people with disability from rural and remote areas.

The DNF would like the ILC Framework to work to improve access to services for people with disability who live in rural, remote and regional areas of NSW. As isolation and fewer service choices (both disability and mainstream) interact to increase complexity, the DNF believes that LACs in these areas should have a lower case load to enable them to encourage and identify innovative approaches.

Recommendation 11

That local area co-ordinators (LACs) located in rural and remote areas have a smaller caseload, with consequent capacity to take on a community development role.

Cultural group

The DNF believes it is crucial that the principles of equity and cultural responsiveness are set out as foundational principles for the ILC Policy Framework. Both are principles which need to be incorporated in the language and strategic objectives of all aspects of the NDIS upfront—including the ILC Framework. This is important because Aboriginal and Torres Strait Islander (ATSI) and culturally and linguistically diverse (CALD) populations are known to be at greater risk of social isolation, and specific culturally competent and culturally responsive action and information is required to connect these groups into service models within the wider community.

It is the view of the DNF that building the ILC Policy Framework on foundation principles of equity and cultural responsiveness is likely to create an NDIS which is able to cater for difference and diversity. In order to ensure the aims of the NDIS are achieved for people with disability from ATSI or CALD backgrounds, equity and cultural responsiveness must be positioned as core principles in the policy framework, alongside individual empowerment. The DNF wants to avoid the risk that people with disability who are from ATSI, CALD and other disadvantaged backgrounds will miss out and be further marginalised in an inequitable service system, especially where culturally competent individual packages are required but not developed.

The DNF asserts that the principles of cultural competence and cultural responsiveness need to be incorporated into key measurable outcomes of the ILC Policy Framework and all aspects of the NDIS.

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Recommendation 12

That cultural competence and responsiveness be embedded in the ILC Policy Framework in the following ways:

- ILC Stream 1 could be retitled 'Culturally competent information and linkages and referrals' to recognise the importance of connecting people with disability with culturally appropriate services.
- All initiatives funded under "Community Awareness and capacity building" (ILC Stream 3) should be built on the principle of cultural competence.
- Within ILC Stream 4 (Individual capacity building), strong community connections should be developed to address potential isolation of people with a disability from ATSI or CALD backgrounds and their carers. This requires long term and sustainable supports for ATSI and CALD clients and their carers and the wider community.
- Specific LACs are appointed from ATSI and CALD backgrounds.
- Cultural competence training be provided to all LACs.

Disability type

The ILC Policy Framework could be strengthened with a demonstration of how outreach and engagement with people living isolated lives will occur — whether that isolation is caused by location, disability type, a lack of access to support or a combination of these factors. DNF members have found that a very active process of outreach and relationship building enables individuals in this situation to seek assistance and maximise benefits from disability supports. Information may need to be repeated through multiple channels, such as follow up letters and/or phone calls after information is given face to face.

A strong and skilled outreach and engagement strategy is integral to the NDIS achieving equity of access. There are multiple ways in which the NDIS could be alerted to people living in isolation, for example by health, public housing, criminal justice and child protection services. The NDIS then needs to respond using a skilled and experienced worker who can first put in the time to establish a trusting relationship with the person.

The efforts of the Intellectual Disability Rights Service in the Hunter trial site show that a worker with a trusted relationship can successfully support a person living on the fringe to become a participant in the NDIS. IDRS has relationships with many offenders with intellectual disability through its provision of volunteer support people in police interviews and in court. The IDRS Hunter Coordinator has built on these relationships to explain the NDIS to clients and support them to become participants.

Similarly, DNF members expect that many people with intellectual disability will require disability specific support from the ILC system, because they will be ineligible for an ISP but will require substantial disability support in times of crisis or transition. For example, they may need assistance negotiating the health, justice or public housing systems, understanding mobile phone contracts, or responding to official correspondence from agencies such as Centrelink or public housing. Allowing organisations latitude in services provided, as suggested in Recommendation 9 above, may stop some people requiring ISPs and would go some way towards addressing the issue of crisis support and would render the ILC framework more responsive to people with disability who are ineligible for individualised funding under the NDIS.

The DNF believes that in some cases, ILC services need to be appropriate for, and responsive to people with specific types of disability. For example, DNF members report a dearth of services

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available to people who are deafblind, with workers often sent to support clients who are deafblind without having any experience in how to communicate with them.

Recommendation 13

That some LACs be funded in recognition of their expertise in providing support to people with a particular types of disability.

Recommendation 14

That LACs be resourced to support at times of crisis where this support is not available through other services.