

# Information, Linkages and Capacity building funding

By Leticia Hodson

The National Disability Insurance Scheme (NDIS) is a major change for people with a disability and the way disability services are delivered in Australia. It is a social reform on the scale of the introduction of Medicare and compulsory superannuation – two safety nets we now all take for granted. The focus on the initial roll out of the NDIS was individual support in the form of plans where people receive reasonable and necessary supports to achieve their goals.

But there is more to the NDIS than just individualised support. The NDIS changes the landscape for organisations who provide services for people with a disability. As people gain more choice over the kinds of services they want to access, the focus moves away from disability specific supports and spreads across the rest of the community creating a competitive marketplace for providers. This means that current disability specific organisations will no longer receive the block funding they received from government to provide their services and mainstream organisations need to improve their capacity to include people with disabilities as more and more people use their plans to access the community in broader ways.

One of the ways that the National Disability Insurance Agency (NDIA) is meeting this need is through the Information, Linkages and Capacity building stream of funding (ILC funding).

The ILC Commissioning Framework has an overview of how the ILC will operate

<https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc>

This article is a summary of that information.

According to the Australian Institute of Health and Welfare, 89% of people with a disability will not be eligible to enter the NDIS<sup>1</sup> due to being outside the eligibility criteria (such as being over 65 or their disability not being permanent, etc.). ILC funding will be key to ensuring that all people with a disability have the capacity and opportunity to access the community by funding projects and programs for people who do not have individual plans under the scheme.



<sup>1</sup> [https://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0012/231420/sub058-disability-agreement.pdf](https://www.pc.gov.au/__data/assets/pdf_file/0012/231420/sub058-disability-agreement.pdf)





The NDIA anticipates that ILC funding will contribute to the sustainability of the scheme by supporting community organisations to include people with disabilities into the same activities as everyone else and reduce the reliance on specialist supports over time.

ILC funding is primarily occurring in the form of grants to organisations but is expected to expand into other areas such as co-investment, innovation and the delivery of research and evidence about inclusion to the community.

But for now, organisations apply for grants to carry out particular activities. These activities need to fit prescribed *activity areas*, fit within one or more *focus areas* and deliver prescribed outcomes for people with a disability.

There are five kinds of activities that will be funded by ILC in the future:

1. Information, linkages and referrals,
2. Capacity building for mainstream services,
3. Community awareness and capacity building,
4. Individual capacity building, and
5. Local area coordination.

The fifth activity area (LAC) is being managed separately to the other four and the Commissioning Framework outlines how the remaining four are funded and managed.

In summary, ILC is intended to **improve the capacity** of individuals to access the community by funding activities that are not covered by their plans and **improve the opportunity** for people with disabilities (whether they have access to the NDIS or not) to access community activities by improving the way those organisations include people with disabilities.

This means the states and territory Down syndrome organisations have lost a lot of the core funding that used to fund services, programs and workshops. Down Syndrome Australia has been working with the states and territories to help secure ILC grants to ensure that these services continue.

We have also been successful in receiving grants to expand the resources that DSA provide including the Community Inclusion Toolkit, the National website project, *Voice* expansion project and the development of new resources such as a new app and animation for schools.

*Leticia Hodson is the managing editor of Voice, the journal of Down Syndrome Australia.*

# How does the NDIS change the landscape for Down syndrome organisations?

As the NDIS rolls out across the country, this major reform is changing the way the state and territory organisations receive funding to provide the resources and services they have always provided. This move to Information Linkages and Capacity (ILC) funding creates new opportunities for organisations as well as challenges for existing services to adjust and create sustainable streams of funding into the long term. We take a look at the ways some states are adapting to the change.

## From Down Syndrome New South Wales

Down Syndrome NSW is taking active steps to embrace a new NDIS business model that will ensure we are helping to sustain our own future as a viable not-for-profit. Our journey as an NDIS service provider has similarities to the goals of the NDIS being a person-centred scheme to help enable a person with disability gain more control and self-management of their lives. However, this transition to the NDIS doesn't come without its challenges.

UP!Club, a peer group connection program for adults, is our flagship program. Government funding for this project has now ceased. We have registered as an NDIS service provider and are currently in transition to a more financially sustainable model that will allow us to continue to develop this program into more clubs, expanding into regional areas.

Although there has been some resistance to the new model – a program that used to be 'free' to users must now be paid for – we emphasise the *transition* part of the model. We have provided those members with support in pre-planning and planning meetings, advising where they need to apply their request for funds in their plans in order to provide for UP!Club activities.

We currently have over 50 participants with signed Service Provision Agreements for UP!Club.

Furthermore, we are currently developing a strategy to eventually include pre-planning and plan support, as well as behavioural support, as part of our NDIS service provision. It will develop in the same way as UP!Club, once those members have transitioned into having funds available in their plans.

Open and transparent communication as we evolve through this transition, and continued support in planning, are the keys to achieve best outcomes for both ourselves as a service provider and our members.

## From Down Syndrome Queensland

Here at Down Syndrome Queensland, we have found that the introduction of the NDIS has challenged our organisation in two ways.

Firstly, across all of Queensland, our members have (or will soon) transition to the NDIS and we have been providing support to them through this process in the form of workshops, pre-planning resources, pre-planning meetings and advocacy with any NDIS issues. We have had positive feedback on our support and overall the transition to the NDIS has been positive for many people, particularly for those who were receiving no support prior to the NDIS. We continue to work with and support those that are having issues or require advocacy support with the NDIS.

Secondly, during 2018 we provided information and support services via phone, email and face to face to well over 900 people. We have helped our community across the whole state from Cairns to the Gold Coast as well as maintaining and updating information resources and publications on our website and Facebook page. We also provided regular events and functions to over 150 people through our social club, Continued Education Program, Challenge weekends, choir and music therapy. Historically, Down Syndrome Queensland received some block funding from the Queensland government which paid for some of these activities. This funding is being phased out with the introduction of the NDIS and it is vital that we are able to transition to NDIS Information, Linkages and Capacity Building (ILC) funding during 2019 for these information and support services. We are also pursuing other sources of funding such as grants in order to expand on our current support and services.

Overall the NDIS is a good thing for people with Down syndrome. As with any large-scale change such as this, it doesn't come without its challenges but ultimately,



putting the choice and control in the hands of the people with the disability is the right thing to do. We will continue to work with our members to support them through the change and will pursue the organisational change required to operate effectively under the NDIS and ensure that we can continue to build on the work we have been doing in Queensland since 1976.

### **From Down Syndrome Victoria**

Surety of funding is critical to the ongoing survival of NFPs like Down Syndrome Victoria (DSV) and the transition from the recurrent state-based information funding to the uncertainty of applying for NDIA federal funding under ILC is a major change and adjustment to the way that we operate. NFPs that were previously funded by state governments and philanthropic funding to provide services now have to become service providers to access funding through the NDIS, which is new ground for many NFPs.

DSV has gone through the expensive and arduous process of registering to become a service provider and then scrutinised our services to see what will align with the NDIS. Club21 (a social peer support group for adults) had an uncertain future due to its reliance on philanthropic grants since it started. In 2018, Club21 became a DSV service available for participants to access with NDIS funds under 'group-based community, social and recreational activities'. To ensure that we did not exclude those who were not NDIS participants due to the staggered roll out, those without an NDIS plan were still able to attend under the previous payment arrangement. To ensure its financial viability and continuation, Club21 will need to transition to full NDIS service delivery in 2019 as it is no longer funded philanthropically. Overall most Club21 participants and their families were supportive of this changed model and understood the necessity for us to move to a NDIS service.



Parent and carer training was another opportunity for DSV to develop a suite of workshops across all ages that could be accessed with NDIS funds under 'capacity building supports'. Previous DSV workshops had been heavily subsidised and whilst that had kept the cost down it was also problematic as we were dependant on applying for funding when it was available and could not develop a suite of workshops. In 2018 we delivered 11 workshops covering from birth through to aged related issues such as dementia with 224 parents and carers attending. The NDIS provided this opportunity and DSV will continue to hold workshops that can assist people with Down syndrome to live a fulfilled life. The NDIS will forever change the landscape of not for profit associations like Down Syndrome Victoria. But with early planning, forward thinking and appropriate ILC funding to fund services the NDIS will not fund, we are hopeful that DSV will be able to offer a mix of services and continue to provide support for those with Down syndrome and their families.