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The Secretary  
Legislative Council Committee Government Administration B  
Parliament of Tasmania  
Parliament House  
HOBART TAS 7000

### Disability Services in Tasmania

*"People with disability are the shock absorbers for any volatility caused by poor policy and practice – they are the ones that ultimately feel the impact of systemic challenges."* (Six Years and Counting: The NDIS and the Australian Disability Services System A White Paper | The University of Western Australia).

The Brain Injury Association of Tasmania (BIAT) welcomes the opportunity to make a submission to the Legislative Council Committee Government Administration B Inquiry into Disability Services in Tasmania.

Prior to 31 March 2020 Tasmanians with disability and their families and carers had access to a variety of support organisations which provided information, advice and referral services. These organisations, including the Brain Injury Association of Tasmania (BIAT), received State Government block funding through disability service grants.

In addition to providing a specialist brain injury information, advice and referral service, BIAT also undertook systemic advocacy, community awareness, and professional development activities, and was recognized as the peak body for brain injury in Tasmania.

Under a bilateral agreement with the Commonwealth, Tasmania agreed to pay a fixed annual contribution to the NDIS, set at \$233 million in 2019-20, then escalating at 4.0 per cent per annum. This contribution represents the total of Tasmania's disability budget and, as such, funding ceased for organisations servicing Tasmanians with disability who are not on, or eligible for, the NDIS.

The expectation was that BIAT and other similar organisations apply for nationally competitive, short-term, project grants under the NDIS Information, Linkage and Capacity Building (ILC) Strategy, and that these ILC grants would fill the gaps created by the cessation of block funding to the disability support organisations.

At this point it should be noted that the Australian Institute of Health and Welfare (AIHW) estimates that 89% of the estimated 4.3 million Australian people with disability will not be eligible for an NDIS individualised funded package (IFP), but will need support to connect with or access community and mainstream services such as health, education, housing etc. They will, most likely, be dependent upon the Information, Linkages and Capacity Building (ILC) Strategy to meet their needs.

The National Disability Insurance Agency (NDIA) states ILC is the component of the NDIS which provides information, linkages, and referrals to efficiently and effectively connect people with disability, their families, and carers with appropriate disability, community, and mainstream supports, irrespective of whether the person is eligible for the NDIS or not. It plays a significant role in ensuring all people with disability are supported to live more accessible and connected lives.

Providing nationally competitive grants to organisations to carry out activities in the community, the ILC Strategy however only receives 0.06% of the NDIS budget - \$132 million of the \$22 billion budget in 2019-2020.

People, organisations, and the media have been very outspoken about problems with the NDIS - extensive wait times for equipment and services, thin markets, a shortage of and/or inconsistency between NDIA planners, and inadequate pricing etc; the list is quite extensive. By March 2020, sixty-three (63) reports had been written by universities and industry bodies that identified major weaknesses and improvements needed to ensure success of the NDIS in the context of the wider Australian Disability Services System. (Six Years and Counting: The NDIS and the Australian Disability Services System A White Paper, University of Western Australia).

The Information, Linkages and Capacity Building Strategy on the other hand has received very little attention to date. Given the ILC is absolutely critical if better outcomes are going to be achieved for people with disability and their families, this needs to change!

### ILC Background

After a series of nationwide consultations in 2015 and 2016 around what an ILC Framework should look like, the NDIA apparently disregarded much of the information provided at the consultations and began delivering ILC initiatives in 2017 through a grants process and through Partners in the Community.

Some nationally competitive 12-month grants were made available and, in 2017-18 disability organisations in NSW, ACT and SA were able to tender for jurisdictional grants. TAS, QLD and VIC were 'next in line' for jurisdictional grants with preparation well underway by organisations in these States for this to occur.

Not only did the ILC 'goal posts' then move, the whole game changed. Towards the end of 2018, the NDIA acknowledged the rollout of the ILC program had been problematic; that they had "learned a lot about what works and what doesn't during the early implementation of the ILC program and have been listening to feedback from the community and key stakeholders." As a result, they changed the approach to the way they invested in building individual and community capacity, launching a refocussed Strategy in December 2018.

Interestingly the feedback from the community and key stakeholders -

- annual grants are administratively burdensome
- one-year grants provide too short a time to make a difference
- a more strategic approach should be taken
- outcomes from programs should be measurable
- the capability of the organisations involved in the ILC program should be enhanced

was the same information they had provided to the NDIA during the initial consultations 3 years earlier.

Implementation of the new Strategy began in early 2019 with the commissioning of a three-year ILC National Information Program (NIP); of the 37 NIP grants awarded no Tasmanian based organisation was successful in this grant round. The lack of commitment to local, place-based programs delivered in each state and territory by local service providers is evident in the exclusion of Tasmanian initiatives approved.

Three other grant rounds – Economic and Community Participation (0 Tasmanian based organisations successful from 28 grants awarded), Individual Capacity Building (6 Tasmanian based organisations successful from 80 grants awarded) and Mainstream Capacity Building, with a focus on health (2 Tasmanian based organisations successful from 28 grants awarded) - were progressively rolled out over the next 12 months.

In mid 2020 the Information, Linkages and Capacity (ILC) Building Strategy transitioned from the National Disability Insurance Agency (NDIA) to the Department of Social Services (DSS). The rationale for the move being that through this transfer ILC will be aligned with the National Disability Strategy, ensuring a strong connection with other national programs including disability employment services, disability advocacy, the new Disability Information Gateway and the recently reformed Carer Gateway.

When the transfer of ILC to DSS was announced last year, it was also stated that "DSS is leading a review and consulting broadly on future directions for ILC." As far as BIAT is aware this has not occurred and there have been no further updates re this. Other than monitoring grants transferred from the NDIA, the only DSS ILC activity during the past 12 months has been to offer 2 one-year grants – Economic Participation, and Social and Community Participation (despite the NDIS acknowledging that one-year grants provide too short a time to make a difference).

These grants closed on the 8<sup>th</sup> of December 2020 and to date successful grant recipients are yet to be notified.

The ILC Strategy is not fit for purpose and is failing Tasmanians with disability who are not on, or eligible for, the NDIS.

The Brain Injury Association of Tasmania (BIAT) believes the ILC Strategy - a project-by-project strategy with a narrow focus on a limited range of outcomes - is not fit for purpose. The Strategy does not take into consideration the broad array of activities most ILC type services provide and it does not consistently adhere to the NDIA's espoused value of "place-based responses to meet local need."

Projects are primarily single focussed and time limited; whether one year or three years is purely semantics. The majority of ILC type organisations, particularly those that lost their block funding, are not single function; they are the community's safety net, responding to need and providing a wide range of supports and services. What these organisations need is surety of ongoing funding, not a drip feed of project funding that many don't have the resources to apply for, or if they do invest time and resources into the application process, may not be successful.

Whilst in the short term ILC will provide some programs and supports not previously available, in the long term it 'offers' expensive bandaid solutions that do not contribute to an effective, sustainable, efficient, and reliable supply of services to stakeholders and for government.

BIAT is concerned that the capacity of the Tasmanian disability sector to deliver ILC services may be diminished by the time a 'fit for purpose' strategy is developed and implemented. Short notice by the Tasmanian Government of an allocation of bridging funding initially granted for the period 1 June – 2 December 2019, then extended to 31 March 2020 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.

Organisations may disappear... the problem will not

People disadvantaged by flaws in the ILC Strategy include Tasmanians living with or impacted by acquired brain injury (ABI); people for whom the Brain Injury Association of Tasmania has been providing services and supports to for the past 22 years.

There is an inherent lack of awareness and understanding of brain injury in the community. Brain injury can be difficult to diagnose, is rarely screened for, and is often overlooked when another injury is present.

This underdiagnosis and lack of community understanding is compounded by the fact that many impacts of brain injury are often 'hidden', cognitive based issues such as memory and communication difficulties. This can create problems for people with brain injury (PWBI) in the community when their behaviours are misunderstood and their needs are not supported.

Research shows brain injury has a direct impact on:

- Suicide rates – people with brain injury are 2 to 5 times more likely to die by suicide;
- Mental illness – people with acquired brain injury (ABI) are more likely to suffer from mental health problems compared to the general population;
- Substance abuse – substance abuse prevalence rates approach or exceed 50% for people with brain injury, spinal cord injuries or mental illness, in striking contrast to 10% of the general population;
- Employment – 31% of people with disabilities are in full time employment compared to 17% of people with ABI; and
- Homelessness – an ABI can exacerbate and magnify the risk factors associated with homelessness including family breakdown, loss of social support networks, lack of affordable housing, family violence, unemployment, illness, drug and alcohol use, violence and/or criminal behaviour.

Brain injury is also a significant consequence of, and contributing factor to, family violence and for people with brain injury parenting can present complex challenges.

What the Tasmanian Government (and other State and Territory Governments) fail to realise is that whilst organisations may disappear, the problem will not. For example, a person with brain injury, who does not receive the supports needed, will appear with multiple issues somewhere else in the system, most likely the revolving door of prison, and/or homelessness services and/or mental health services, and/or the acute healthcare sector, and/or alcohol and drug services, and/or family violence services... the list goes on. The cost may have shifted from disability support, however it will be significantly higher for State and Territory Governments at the next stage, and the next, and the next.

Research also shows the care burden on families is much higher following brain injury; the right supports can do much to alleviate this care burden on families. If people with brain injury do not get these supports not only will they present more often in our overburdened health system, their families will too.

### Specialist versus broad knowledge

A brain injury is potentially one of the most devastating disabilities as it can impact on virtually every aspect of what we think, feel, say, and do. Whilst the funding BIAT received for its information and referral service has ceased, the requests for information and referral have not; BIAT is still the first point of contact for people living with or impacted by brain injury.

One significant gap BIAT has identified is the lack of support for people with cognitive impairment to go through the NDIS process - to understand requirements, comprehend and complete paperwork, gather evidence, meet designated timeframes etc.

There is an expectation that NDIA Local Area Co-ordinators (LACs) will fill the information and linkage gaps for people not on or eligible for an NDIS IFP. For people living with or impacted by brain injury, this expectation makes a presumption that all LACs are knowledgeable across all aspects of all disabilities including brain injury; that they have a detailed understanding of brain injury and know what supports and services – disability, mainstream, and community – exist for people with brain injury.

In Tasmania, BIAT has found this not to be the case. LACs regularly contact BIAT to ‘tap into’ the specialist brain injury information and knowledge BIAT has accumulated over many years. It is BIAT’s firm belief that a good LAC should not know everything about every disability type but should know where they can go to get the specialist information they need. That information and referral source however has to be there for the LACs to access.

Given the broad range of tasks allocated to them and increasing demands on their time and for their services, there is also a question around the capacity of LAC’s to adequately respond to requests in a timely and comprehensive manner.

Synapse, the Queensland based brain injury organisation that was successful in the ILC National Information Program grant round, stated in their grant application that they would have a physical presence, delivering brain injury information and referral, in each state and territory. BIAT’s expectation was this would assist in filling the brain injury information gap, predominantly for people who are not eligible for the NDIS, created when its funding for this service ceased. To date Synapse do not have a physical presence in Tasmania and the gap continues to grow.

### Ongoing Sustainability

The Legislative Council Inquiry Terms of Reference make particular reference to ‘Funding for organisations that service those not eligible for the NDIS’; with ILC grants (assuming they are successful) often their only source of disability funding, ongoing sustainability is a major concern for these organisations.

This concern is compounded by ILC Program Guidelines stating that ILC funding cannot be used to apply for an ILC Grant. With the ILC strategy being a nationally competitive grant process, quality applications take a significant amount of time and resources to develop. If organisations now only have ILC funding, how are they expected to resource further grant applications?

Furthermore, ILC grant money can also only be used “to pay for the portion of operating and administration expenses directly related to the project as per the grant agreement”. Consideration needs to be given as to how, without infrastructure funding to exist, smaller ILC type organisations will be in a position to apply for further ILC funding, or any funding for that matter.

Earlier ILC grant rounds attracted applications from organisations that, prior to the introduction of the NDIS, would not have applied for or received disability funding. Grants, such as the one provided to Little Athletics Australia Ltd, to deliver true inclusion of children with disabilities in competitive athletics, is a good example. This project delivers outcomes - upskilled and accredited Little Athletics centres - which are sustainable without the need for ongoing ILC grant funding.

However, many other projects, which are for establishing and/or piloting services and supports, are not sustainable without ongoing security of grant funding. With each ILC grant round an increasing number of projects are falling into this category. This creates a significant risk that projects will commence, deliver positive outcomes for people with disability, but then not be able to continue as either further grants are not available or the pool of ILC resources are diluted by the increasing number of organisations needing on-going funding to continue their projects.

### Tasmanian Government responsibility to people with disability

Whilst the Tasmanian Government may have handed all disability funding to the NDIS, it still has a responsibility and an obligation to ensure the Tasmanian taxpayers' dollars it is providing to the Commonwealth for the Scheme, meets the needs of ALL Tasmanians living with disability, not just the ones who are deemed eligible for an NDIS individual funded package.

If ILC is the Commonwealth's solution to meeting the needs of people with disability who are not on, or eligible for, the NDIS then the Tasmanian Government must do everything it can to ensure this strategy is fit for purpose and, equally as important, that there is greater investment in ILC.

An important function of ILC is to grow social capital; the current approach however may not achieve this resulting in decreased social cohesion and social capital. Too little is being done too late to address the concerns raised by ILC type organisations, resulting in the very real risk that services, with years of knowledge, expertise, and established partnerships, built up over many years and currently delivering an array of services addressing unmet need, will disappear due to a lack of funding.



The NDIA and State and Territory Governments need to consider and answer the question how will social capital, built up over many years, be regained if these organisations are lost to the community.

The NDIA needs to also recognise there are 'square pegs' that won't fit into their one size fits all 'round holes'; organisations that are small in size but big on reach; organisations that run on the 'smell of an oily rag', 'punch far above their weight', and deliver a myriad of different but essential services and supports to people and families/carers every day. Although not fit for purpose, ILC is currently their only lifeline and, as such, is critical to their survival.

Given that a premise of the NDIS is investing in people with disability early to improve their outcomes later in life, and the promise that no person with disability will be worse off under the NDIS, a far greater investment than 0.06% of the NDIS budget is needed to meet the needs of the 89% of Australians living with disability who will not be deemed eligible for an individualised funded package.

#### Learn from mistakes

BIAT acknowledges that the rollout of the NDIS was always going to be difficult and mistakes were going to be made. Good leadership, however, means that we learn from this experience and modify our approach in a timely manner.

A 2015 Senate Inquiry found the Indigenous Advancement Strategy (IAS) program was plagued by poor communication, uncertainty over continuity of funding and had a confusing application process, with reductions in funding and timeframe commitments. Programs had been collapsed into funding streams, and spending cuts with many frontline Indigenous programs and services bearing the brunt and still feeling the impact. "The damage has already been caused. So, it's a recovery process," (National Congress of Australia's First Peoples Co-Chair Rod Little).

The new program meant many Indigenous organisations that were already funded, needed to reapply under the new scheme and justify their funding, leaving many services fighting for essential funds through a competitive tender process with no certainty of continued funding, just to be provided with short-term funding agreements at the same amount of funding frozen at 2013-14 rates. Sound familiar?

The Senate Inquiry was called to look at the impact of the new system on service quality efficiency and effectiveness of the IAS tendering process. Ultimately the program was labelled 'deeply flawed' and the government was urged to make substantial changes.

Learning from mistakes made with programs such as the IAS, and making the changes needed to the deeply flawed ILC Strategy, without the need for a Senate Inquiry, would be a positive and much needed step forward for all Australians living with disability and the ILC type services that support them.



## Conclusion

In conclusion, repeated changes to, and experimentation with, the NDIS ILC Strategy, and failure to plan to meet the gaps and unmet needs arising from the flaws in, and repeated changes to, the ILC Strategy means many Tasmanians living with disability who do not meet the NDIS eligibility criteria, are likely to end up far worse off than they were before the introduction of the NDIS.

Since its initial introduction in 2017 there have been several changes to the ILC Strategy, yet it is still not fit for purpose. This, and the failure of both the NDIA and State and Territory Governments to address the resulting gaps, will continue to result in many people with disability not receiving the services and supports they need.

Investment in an ILC Strategy that is reflective of and responsive to community need would be cost-effective, reducing the reliance of some people with disability on Individual Funding Packages. However, we cannot reap the insurance benefits of the NDIS if 89% of people with disability receive no support.

The Tasmanian Government signed Tasmania up to the NDIS; their job and responsibility to Tasmanians living with disability did not stop there. The Tasmanian Government is legally and morally obligated to ensure that no Tasmanian living with disability is worse off under the NDIS

Yours sincerely



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