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DARWIN COMMUNITY LEGAL SERVICE

# NDIS Thin Markets Project

## Who are we?

Darwin Community Legal Service (DCLS) is a multi-disciplinary service providing legal advice and assistance to the Top End of the Northern Territory. DCLS has a specialised Seniors and Disability Rights Service (SDRS) providing advocacy support in the areas of ageing and disability. We support people with disabilities, their family or their carers, to access the NDIS. The SDRS team is also supported by a specialist NDIS Appeals Project Officer who provides assistance to participants and their carers in navigating the appeals process for NDIA decisions.

Almost every person with a disability who approaches DCLS for assistance with NDIS issues is impacted by a thin or non-existent market for services. We are often placed in a difficult position trying to provide support to vulnerable individuals where there are simply no services available.

## The Northern Territory context

The NDIS Thin Markets Discussion paper refers to five thin market challenges:

- Geographic Isolation,
- Vulnerable Clients,
- Higher Operating Costs,
- Workforce, and
- Temporary supply gaps during transition.

NDIS participants in remote NT locations face every one of these issues every day, and each challenge impacts on the others. For instance, geographic isolation results in higher operating costs overall, and also makes it exceedingly difficultt to attract and retain suitable staff. Similarly, isolation exacerbates participant vulnerability as client needs become increasingly acute in the absence of suitable, on-going service provision.

NDIS participants in the NT are effectively discriminated against because of the lack of a genuine market. The market-based model for disability service delivery simply does not work in a jurisdiction with (i) a low population base, (ii) participants spread sparsely across remote areas, and (iii) clients with high levels of disadvantage. Ultimately, it is not generally viable to run a profitable service in the NT.

People with disabilities are entitled to an equitable standard of service that meets their needs regardless of where they live. As a fair and democratic society it is our duty to ensure universal access to essential services for those with disabilities. A model based on ‘competition and choice’ in locations where competition and choice is absent further disadvantages those already battling significant disadvantage. Investment in services must be focused on needs rather than on markets.

## Key issues

- **The market is not always an effective and efficient provider**

A market-based system preferences those living in profitable market segments and discriminates against those most in need. It exacerbates demand on public services and creates significant adverse downstream impacts on productivity, and social and economic participation.

- **There has been a failure to ensure a 'provider of last resort'**

For those who were clearly not going to be supported by a market-based model, "provider of last resort" arrangements should have guaranteed a safety net. However, there has been no clear progress on this issue, despite it being almost twelve months since NDIS was fully rolled-out in the NT. Most disturbingly, clients who live in the NT are worse off than they were under previous arrangements because of the diversion of funding to the national scheme.

The "Provider of Last Resort" seems to have been removed from NDIA language, substituted with a more lowly aim of "Maintaining Criticial Supports".

- **People with disabilities who need support should not be treated as consumers.**

Information about services and pricing is confusing. It is difficult for most people to adequately represent themselves and secure the services they need at a price they can afford. The notion of 'choice' is illusory where there are thin markets and limited services. The competition model should not be applied to vulnerable Australians seeking essential services. These people are not spending discretionary income on leisure products. They are seeking the essential services which will allow them to enjoy a reasonable standard of living.

A genuine human rights-based approach demands a needs-based system, so that vulnerable clients do not become hostage to the vagaries of a consumer marketplace. Under the current system, people with negotiating power who live in large, healthy markets in the cities of the south will continue to be favoured.

- **Packages and funding levels are not translating into services.**

The headlines focus on the number and value of packages, but packages are meaningless if there are no services available. The take up of packages tends to become an inappropriate proxy for need, with investment withdrawn on the basis of a "use it or lose it" approach.

- **One size does not fit all**

While the 'competition and choice' model trumpets 'tailored solutions', it is in reality a standardised approach - and people who don't fit the mould are abandoned.

The report on the roll-out of the Barkly Region Trial in NT identified the 'competition and choice' model as ineffective. Yet NDIS was rolled out without regard to the model's serious limitations for application to remote areas. Specifically, the Barkly trial evaluation found that providers were being discouraged from entering remote markets because of (i) poor infrastructure for service delivery, (ii) inadequate pricing structures set by NDIA, (iii) small numbers of NT participants and (iv) problems with staff recruitment and retention. The report highlighted the considerable difficulties experienced by Aboriginal people negotiating the very real barriers to access.[1]

[1] National Institute of Labour Studies, *Evaluation of the NDIS, Final Report*, February 2018

- **Quality regulation – poor service or no service.**

Quality regulation is important in thin markets because of the potential for monopoly providers to engage in price-gouging, or to reduce service standards. However, service providers in thin markets also suffer from high costs, and logistical difficulties in seeking to recruit staff with skills and experience. In remote areas in particular, any service is better than none. Quality regulation needs to achieve a balance which promotes quality services but does not set unachievable goals or penalise providers.

- **Workforce and informal supports**

Recruiting and retaining staff in the NT is difficult in the disability industry, where remuneration is low and the cost of living is high. Caring responsibilities in the NT most often falls on friends and family, yet they are insufficiently recognised. In a vicious irony, their willingness to assist often penalises the participant by reductions in plan provision.

- **Lack of available services outside urban areas leads to isolation and vulnerability**

The 'postcode lottery' – where your location rather than your level of need determines what services you will receive - needs to be addressed. Lack of access to services compounds isolation and vulnerability, potentially exposing people to abuse and neglect.

# Market Challenges

## *Geographic Isolation*

Lack of services

Almost all of the NT is considered remote and service challenges prevail. Remote locations are characterised by small populations, minimal infrastructure, and a lack of ancillary services. These areas cannot sustain profit-based service delivery, so basic services are generally provided by government or not-for-profit providers. These may include mobile, occasional services, or support to travel to regional hubs for services. Of 707 registered providers in the NT, only 18% were active[2],and there continues to be a chronic shortage of services across the Northern Territory. Service providers are rarely willing to travel to remote communities or are not appropriately reimbursed for their costs.

Participation in the NDIS is inhibited for those in remote areas as evidence from allied health professionals is often required to meet the access criteria. Specialist medical services are also in short supply, which creates issues for participants needing medical evidence to support applications. DCLS is aware of many clients on waiting lists of twelve months or more to receive services from neurologists, rheumatologists, ear nose and throat surgeons, and other specialists. Recent interaction with providers indicates that there is a ten-week wait time even for urban Darwin participants to see an occupational therapist. Specialised allied health services are also largely unavailable in the Territory, forcing participants to travel interstate at significant personal cost. DCLS is currently supporting two clients with visual impairments who are having to fund their own travel to access specialist occupational therapists.

[2] COAG Disability Reform Council Quarterly Report, 31 December 2018.

Increasingly, DCLS observes that in the absence of services for remote participants, funds are being withdrawn from plans, rather than efforts being made to ensure services are secured.

For example, B is a client from Ngukurr (635 km from Darwin) who suffers from. severe stage Machado-Joseph disease. She initially received a large amount of funding in her plan which was directed at purchasing supports to allow her to stay living in her community. When her plan was reviewed recently, the NDIA reduced her core support funding by 45%. In an email explaining this decision, the NDIA advised that her core funding was reduced because of 'under-utilisation and thin markets". A further nine NDIS participants in Ngukurr incurred similar funding decreases during plan reviews because the services they so desperately need are not available. Participants on nearby Groote Eylandt are suffering similar reduction, with their plans being cut by an average 31% largely due to lack of services.[3]

It becomes a vicious circle: where participants cannot access the NDIS, demand and service availability declines. Statistically, the extent of the problem is diminished and disguised, while some of the most vulnerable people in Australia are denied access to essential services.

No travel, no access

While services are not available in remote locations, NDIS plans do not include travel to required services so participants in thin markets miss out.

M - a two-year-old client diagnosed with Autism Spectrum Disorder (ASD) severity level 3 - required interventions of speech and language therapy, occupational therapy and physiotherapy. There is only one speech therapist in the whole of NT, only limited occupational therapy and physiotherapy, and no substantive language therapy. None of these services apart from physiotherapy is available in Nhulunbuy where the client lives. Incredibly, flights to Queensland - where he was able to access intensive therapy sessions with all providers - have not been approved by the NDIA, who maintained that the cost should be met by his parents.

Another client, non-verbal and severely disabled, sought assistance to fly from Maningrida to attend a review meeting of his plan in Darwin. He was refused because travel is not allowed under a plan. Previously DCLS had arranged for him to attend in Darwin for plan meetings by combining the visit with respite, but respite is no longer allowable under his plan.

## *Vulnerable clients*

There is often an overlap between vulnerability, disadvantage and geographic isolation. Almost 80% of Aboriginal and Torres Strait Islander peoples in the NT live in remote areas.[4] Further, almost all of the Northern Territory (except Darwin and surrounds) is classified at the most disadvantaged level on the Social and Economic Indexes for Areas.[5] More than three-quarters of NDIS participants in the NT are Indigenous, and 38% come from a culturally and linguistically diverse background.[6] In addition to facing significant social and economic disadvantage and poor health outcomes, Indigenous participants find it difficult to access services because they live in remote locations and the few services that are available are not culturally appropriate. CALD participants also face similar language and cultural barriers. These participants need to be assisted to engage with the NDIS and create demand for services. However, their only source of support is often from a family member, friend, or independent advocate.

[3] See 'Fund cuts hit NDIS remote customers', *The Australian*, Amos Aikman, 22 March 2019.
[4] ABS, Census 2011
[5] ABS, SEIFA 2016
[6] NDS State of the Disability Sector Report 2018, p 49.

It is particularly difficult for vulnerable clients to exercise choice and control because of the challenges in accessing appropriate information and the asymmetry of power. Only limited independent advocacy support is available to participants but the benefits are significant, with plans increasing by 30% on average where an advocate has been used. Research commissioned by the Disability Advocacy Network Australia estimates that independent advocacy delivers substantial economic benefits, including improved education and employment outcomes. It also frees-up resources in justice, health and accommodation services, with an estimated benefit of $3.50 returned for each dollar of cost.[7]

## *Higher Operating Costs and appropriateness of funding models*

Higher operating costs are a consequence of the lack of economies of scale and the difficulties involved in sourcing goods and services that are not available locally. Rents are high and accommodation is at a premium in the NT, particularly in remote areas. Increased costs are also associated with the cohort of participants, since provision of services to clients with high levels of disadvantage in different cultural contexts is complex and time-consuming. The cost of accessing services may require the provision of interpreters, or specific additional supports from family or elders. Appropriate benchmarking and price setting needs to take into account the real cost of accessing services in very remote locations where the participants live. By way of example, a service in Yirrkala in East Arnhem Land reports being charged $1600 freight for two walkers, a wheelchair and a walking stick, more than the equipment itself was worth.

The individual subsidy model of funding is not sustainable in most of the NT because the economies-of-scale do not exist. This creates a significant administrative burden, particularly for small providers, who have to direct resources away from participants. The uncertainty of funding for ongoing employment, infrastructure and equipment threatens the viability of services, and presents challenges in achieving quality standards. Block funding models, such as those used under the Aboriginal and Torres Strait Islander Flexible Aged Care Program, should be adopted as the standard funding model for remote communities.

## *Workforce*

Recruitment and retention of workers in the NT is always a challenge, particularly when NDIS pricing does not appropriately reflect the lack of skilled workers and the challenging and isolated circumstances in which they work. Housing is another significant obstacle to attracting workers in the NT.

The void is often filled by shifting the load to family and community. It is estimated that one in four (and in remote areas one in three) Aboriginal or Torres Strait Islander people aged over 14 provided care for a person with a disability, long term health condition, or old age. (By contrast, In the general population this figure is less than one in ten.[8]) Ironically, carers are often penalised for this contribution. They are unable to participate fully in the workforce because of their caring responsibilities and consequently are removed from CDP. Yet they receive no recognition or remuneration for their work.

The role of community and family members in providing support where no services exist should be formally recognised. There must be an investment in capacity building, dedicated training in remote areas, and provision of resources, remuneration and respite.

CoS services are often critical to helping participants access services using their plan. CoS providers are therefore a key agent in strengthening the market for services because they can

[7] DANA, *Independent Cost Benefit Analysis of Australia's Independent Disability Advocacy Agencies,* 2017

[8] Australian Bureau of Statistics, *National Aboriginal and Torres Strait Islander Social Survey 2014-15,*

enhance participant engagement. DCLS has observed a growing gap between available CoS services and participant demand - which is being compounded by clients receiving less funding for CoS supports in their plans. In a number of cases, CoS supports have not been automatically offered to participants in the planning process, leaving them without a critical tool for accessing services and participating in the market.

At the time of writing, DCLS are aware that there is an average 6-8 week wait for urban Darwin participants to access Coordination of Supports (CoS) services from providers. CoS providers in Darwin are now refusing to take on new referrals from NDIS clients. Wait times for CoS services in regional and remote areas are even longer, due to the small number of providers.

## Recommendations

1. Provide a government-backed safety-net of services to ensure that people with disability have access to the same standard of services, regardless of where they live. The "provider of last resort" supports need to be both resourced and implemented urgently to ensure the gap in accessing services does not continue to grow.

2. Facilitate access to services by ensuring travel is funded where needed to access a plan, or services under a plan.

3. Commission demographic work and mapping of services alongside assessment of need to better plan provision of services, identify gaps and allocate resources.

4. Resource advocacy support to enable choice and control by clients.

   Accessing the NDIS is a complex process for most clients, particularly those facing language barriers and limited access to technology. Where participants cannot access the scheme, demand reduces and services diminish. Maximising access is therefore important to combat thin markets in the Territory. In the NT, independent advocates are a particularly important resource for assisting people with disabilities to engage with the NDIS and to help them navigate the barriers of social disadvantage, cultural difference and geographical isolation. Adequate resourcing of advocacy services is therefore an important tool in addressing thin markets.

5. Ensure flexible design of service provision (vs packages), with the Commonwealth Government working in partnership with local organisations to ensure appropriate services are available and delivered.

   The subsidy model should be replaced with block funding models in areas with thin markets and where community and not-for-profit organisations to enable them to support continuity of service, provide appropriate infrastructure, and attract skilled staff. Place based models should be encouraged to better enable service delivery appropriate to needs.

6. Encourage collaboration amongst service providers

   The NDIA should consider establishing formal structures for collaboration between local Coordinator of Support (CoS) providers to source supports needed by groups of participants. At present, CoS providers in the Territory have limited communication with each other and operate in silos, fenced in by the individual needs of their clients.

   Different CoS providers who have clients with similar support needs could source services not otherwise available in their area by approaching providers together. This collective approach to sourcing services 'in bulk' might create demand and 'thicken' the

market in some areas. This practice may already be occurring on an informal basis, but could be fostered by the development of formal structures, such as regular meetings of CoS providers facilitated by an NDIA Local Area Coordinator.

7. Train, develop, support, and adequately remunerate a local workforce providing disability care services.

8. Formally recognise the role and contribution that informal carers make, and invest in upskilling and capacity building, particularly in remote communities.

9. Provide safety in the provision of care and focus on improving quality while ensuring viability of services.

   Applying urban-based quality standards to services in remote Aboriginal communities is neither appropriate nor achievable. Quality initiatives should be focused on building capacity and supporting services to continue to operate even in thin markets.

10. Fund the real costs of needs and services in a way that ensures availability and continuity of care. Pricing need to be benchmarked by area and need to better reflect different servicing contexts. Unallocated funds should be reinvested in areas of greatest needs as determined by objective measurement and not by take up or utilisation of plans.