

Carers Victoria Submission

NDIS Thin Markets Project

June 2019

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership-based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This policy paper was prepared by Carers Victoria's Policy Team.

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Introduction

The National Disability Insurance Scheme (NDIS) is a revolutionary and positive step in making Australia a fairer society. Participants are being supported to live more dignified, active lives and will have the opportunity to exercise choice and control by purchasing supports according to their needs and preferences.

People living with disability do not exist in isolation and unpaid family and friend carers often provide most of the assistance they receive. Victoria has an estimated 736,600 carers providing approximately \$15b worth of support annually. Engaging carers in participant plan development will increase the outcomes of the NDIS – the participant's whole life will be considered rather than a narrow focus on their disability.

The NDIS website states:

The role of families and carers is often essential in supporting people with disability to realise their goals, so it is important to include them in discussions about supports.

Thin markets in the NDIS have significant impacts on participants who are unable to access support services and the consequences of this are frequently borne by family and friend carers.

Carers Victoria response to selected questions

1. What role does your organisation undertake in the sector?

Carers Victoria has worked for over 25 years to ensure unpaid family and friend carers and the people they care for are supported in their daily lives, so all involved have improved health, wellbeing, resilience and financial security.

As the state-wide peak body for carers, Carers Victoria represents and supports caring households throughout Victoria by working directly with them and collaborating with government, businesses and other community organisations to improve services, systems and supports. We provide and connect carers to a wide range of services, including counselling, funding support, respite, education and training. Carers Victoria also offers phone and in-person support to carers and participants to help them transition to the NDIS and build their confidence and capacity to navigate a disability support market.

Through the delivery of carer supports and services, Carers Victoria receives feedback from Carer Support Groups, Carer Support Workers, Service Managers, Carer Advisers and online forums. Two staff are solely employed to help carers negotiate the NDIS. Carers Victoria regularly attends working groups and meetings to represent the voice of carers in the disability sector e.g. the "Every Australian Counts" National Day of Action forum, held at Moonee Valley Racecourse, 3 May 2019.

2. Has your organisation recently supported participants who are affected by thin markets?

Carers Victoria has supported scores of carers, and the people they care for, affected by thin markets, particularly those in rural and regional Victoria.

We have observed how thin markets have existed as long as disability services have and how thin markets usually result in poor participant outcomes, increased costs and a far higher demand placed upon carers and other informal supports.

A good example is the reluctance to include Short Term Accommodation Assistance in participants' plans, artificially reducing demand for residential respite facilities. A thin market will be created if respite facilities are forced to close.

The NDIS website says the National Disability Insurance Authority (NDIA) "...will fulfil its role as a market steward as the disability services market undergoes reform." The market must be managed so that services with high demand, such as accommodation and assistance, can continue operation.

3. Where do you anticipate your constituents will experience thin markets issues in the future? (by location and/or service type)?

Carers Victoria's consultation with carers in Mildura found children with Autism Spectrum Disorders (ASD) had difficulties in access local specialised and early intervention services. Mildura is a large regional city and cannot sustain sufficient services, Carers Victoria has found this difficulty increases the more remote people are.

Carers Victoria's experience indicates participants are most likely to be disadvantaged by thin markets if they:

- have a psychosocial disability
- are in isolated geographic areas
- have complex needs
- have behaviours of concern, and
- have a housing need.

Carers Victoria notes that the NDIS is not one market but is numerous intertwined markets interacting with each other. Also, as the NDIS is very new, thin markets are still emerging and it is difficult to tell if they are expanding, static or decreasing in size.

Carers Victoria notes that carers report thin markets have emerged for the following service types:

- transport state-wide
- support coordination
- specialist support coordination
- Specialist Disability Accommodation and accessible housing in general
- Short Term Accommodation Assistance
- allied health therapists
- participants transitioning from Better Start and Helping Children with Autism (HCWA) funding, and
- adult training and support services, where carers report some providers are exiting the market or capping their services to existing clients.

In relation to support coordination, the effectiveness of the service is limited by the low unit cost per hour for this support. Carers report inexperienced support coordinators and insufficient hours of support coordination in NDIS plans. Specialist support coordination is further limited by workforce shortages of people who have high levels of skill and experience in working with people with disabilities and complex needs and their families.

Recommendation 1: The NDIA constantly monitors the status of thin markets and publishes results allowing providers to plan services adequately.

4. In your organisation's experience, what barriers are affecting the availability of services, and the ability of participants to access services? (e.g. access to information, diversity of services, location and travel, plan budget etc.)?

Carer consultation and feedback have shown a very significant shortage of disability experienced staff at the NDIA. This has also been reported by carers meeting with Local Area Coordinators. While we acknowledge some sample bias, as we mainly get calls due to people not being able to navigate the system, carer feedback shows skill levels within the sector appear low.

A lack of skilled staff has led to some inappropriate support plans. The market cannot grow appropriately to meet needs if demand for some service types is not accurately represented.

For example, Carers Victoria has been informed some respite care facilities in rural areas of Victoria are in jeopardy due to poor utilisation. Local carer support workers report these facilities were fully booked prior to the NDIS. If scheduled, regular short-term accommodation assistance is not available through the NDIS, emergency respite will face significantly more demand, yet facilities to meet this demand may have closed.

Respite is possibly the largest issue carers request assistance with from Carers Victoria, but some carers report planners refusing to include short term accommodation assistance in participant plans.

Other barriers inhibiting participants accessing services include:

- geographic isolation
- lack of public information about the NDIS
- lack of information to Culturally and Linguistically Diverse communities, especially in different languages
- providers "cherry picking" less challenging clients, and
- service providers having difficulty identifying and marketing to suitable participants.

Systemic issues creating unnecessary barriers for participants and their families include:

- inadequate pricing for some service types
- workforce shortages, and
- increased operating costs for providers of doing business with the NDIA e.g. inefficient portal, planning and payment issues.

Carers Victoria notes the changes to NDIS pricing from 1 July. The NDIA must be more responsive to consumer and industry feedback on the real costs of providing a safe, quality and individualised disability support service.

We have observed how LACs and Early Childhood Early Intervention partners appear to have focussed on bi-lateral targets. There has been little invested in

supporting participants and carers to connect with specialist and mainstream services.

Again, the NDIA has a role in the stewardship of the disability market and can be generating the rapid increase in service providers. While the number and types of service providers is growing, it is at a slow rate. Significantly increasing unit cost price in some areas would accelerate the number and types of service providers, particularly in areas of skill shortage such as behaviour support services. Subsequently holding the price constant for a few years would favour more efficient providers.

Another impediment is the lack of skilled planning staff. Carers and participants have reported they cannot get assistance from private support staff and the LAC on how best to develop a program which meets their needs. Some participants have been lost in the system and have not been notified of their status or approved plan.

Recommendation 2: The LACs need greater accountability on supporting participants to activate the supports funded in their plan.

There have also been complaints of very long delays in having plans reviewed by the NDIA when a change is needed.

Recommendation 3: Lift the staffing cap on the NDIA.

One carer reported they made approximately 25 phone calls to different service providers on a list given by their LAC and only had two responses. The published list of providers does not indicate which providers have a waiting list or enough detail to confirm whether they can take on new clients.

Recommendation 4: Make the NDIS website's list of providers more user friendly and more up to date.

Carers Victoria has had two main areas of NDIS enquiry from carers. The first is when they receive a letter and not know what the next step is. The second is when carers and the participants access the portal, the information is overwhelming. People with poor literacy, English language and advocacy skills often do not know what to do or how to best use the NDIS.

Recommendation 5: The NDIS must be marketed in appropriate languages to demographic groups who are under-represented in the NDIS.

Recommendation 6: The NDIA and LACs employ people with disabilities and/or from

diverse language and cultural groups to improve communication with the people they are working with.

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Many participants and carers were comfortable using long-standing specialist disability support organisations where they felt services were generally good and choice was not a major component of core activities. Carers Victoria has dealt with some participants and carers who are unfamiliar with how best to negotiate a new system, with multiple choices on many levels. We are optimistic this will change over time, but it is a problem many people face in the short to medium term. Greater

investment to support participants and their parents/carers will help them become confident and capable consumers who will understand their service agreements and be able to negotiate with providers.

Recommendation 7: Fund an adequate number of planners to support carers and participants manage the NDIS.

5. What short-term and long-term approaches do you believe would best address thin market issues for you?

(e.g. provision of more information to participants and providers about supply and demand, government directly paying a provider to make sure supports are available, bundling of services, different approach to pricing, establishment of an effective e-market etc.)? Are there approaches you would not support?

Carers Victoria has found NDIA pricing of some services does not match the cost of provision which precludes the creation of a functioning market. Scope, a major service provider for people with physical, intellectual and multiple disabilities and developmental delays, has withdrawn from one to one service provision in participants' homes as it was uneconomic to continue providing this service. It has been reported both Anglicare and Australian Unity are considering doing the same.

Recommendation 8: NDIA pricing to accurately reflect the cost of service provision.

Recommendation 9: The NDIA must continuously monitor both the cost of service delivery and the payment fee to the service providers and

publish results.

The growth in demand for NDIS services will severely test the capacity of the market. Research by Curtin University and National Disability Services (NDS) suggests many non-government disability service providers lack the capacity to invest in major growth and two-thirds report they are worried about their ability to provide services with NDIS prices. New providers are hesitant to invest and many small potential providers have found the registration process onerous. The Australian Psychological Society has commented on how many of their sole traders are not prepared to participate in the NDIS due to its third-party registration costs starting at \$9,000.

In the move to a market-based system, many service providers are considering either merging or ceasing to trade in the NDIS. In April 2019 the National Disability Scheme reported within the next two years, 38 percent of providers think it is "very likely or likely" their agency will merge with another. Regional providers are more likely to have this opinion.

The NDIA should only intervene when the market is either failing or is at a significant risk of doing so. The non-government sector must have the capacity and confidence to grow substantially and must not be crowded out.

Recommendation 10: The NDIA should expand the provision of market data to assist providers with their planning and investment decisions.

The NDIA applies modest loadings to prices in regions which the Modified Monash Model determines are remote. The loadings do not adequately reflect the costs of service provision in some regions. Providers have no control over many of the factors determining costs in areas where distances can be vast and suitable workers are in short supply. The method for funding supports in these parts of Australia should be revised to reflect the full impact of local conditions.

Recommendation 11: Revise the method for determining remote locations and price loadings to reflect the full cost impact of local conditions.

However, the NDIA should not be propping up failing providers in thin markets.

Recommendation 12: Have closed tenders from reputable service providers to participate in thin markets if the market is not providing enough competition or an acceptable level of amenity.

Recommendation 13: Government should only provide services as a last resort.

Further recommendations to address major thin market areas:

5.1 Geographic Isolation

- use telecommunications such as Skype to provide some regional services e.g. counselling
- engage local and lower skilled support workers who would be overseen by a skilled worker using telecommunications
- provide higher travel subsidies to workers in isolated areas
- encourage collective bookings of services by participants in areas
- offer tax incentives for skilled workers to be based regionally, and
- have government provide services or provide block funding to service providers
 with a demonstrated skill in the requisite area. Any provider must engage with the
 communities they support in the design and delivery of services.

5.2 Vulnerable Participants

- mandate that highly skilled staff are to be engaged in providing safe, quality support
- pay higher pay rates for experienced and qualified workers, including those with specialist skill sets such as positive behaviour support skills. There is currently only a small gap between pay for lower and higher qualified staff
- have minimum staff qualifications and experience for some roles
- use evidence-based practice to measure how services are best delivered, and
- have more flexibility as to how funds can be spent for participants in thin markets.

5.3 Higher Operating Costs

- have incentives for multi-skilled staff so diverse situations can be provided for
- ensure continuous training is a part of any registered provider's culture
- consider allowing NDIS funds to be used to assist a high needs participant and their carer move to an area where more services are available if they so choose
- grant a priority social housing transfer if a participant needs to be closer to services
- increase the use of telecommunicated service provision where appropriate
- Price gouging can be minimised by having a closed tender from reputable service providers to intervene in thin markets, and
- consider block funding or direct government service provision as a last resort.

5.4 Workforce

- develop a clear and coherent national industry plan, with a strong focus on workforce growth and development, to support the sector's development and transition to the NDIS market. The plan should outline actions, timeframes, accountabilities and monitoring arrangements, and build on the commitments some governments have already made to workforce development projects
- institute a funded, portable training entitlement for disability support workers to acquire specialised skills and qualifications and develop their career across aged care and disability support
- have appropriate remuneration as an incentive to have skilled staff work in required areas
- Review the NDS' Workforce Capability Framework and workforce development tools and resources to see what is transferable to the NDIS
- allow flexibility in work-life balance for staff
- have rewards and recognition for innovation and good quality service provision
- provide tax incentives for skilled workers to operate in areas of high need e.g. geographically isolated

- provide regional grants to train staff similar to the old teaching scholarships,
 where a staff member recipient must spend a number of years working in regional or specific vocational areas
- provide free or subsidised TAFE courses for workers wanting to upgrade skills or family carers wanting to enter paid disability support work, and
- have students undergo practical training and placement, as well as desk-based theory education.

5.5 Temporary Supply Gaps

- set up coordinated regional responses involving government and service providers in areas where a supply gap is expected
- have the NDIA/LAC set up bulk purchasing arrangements for participants, e.g. pool participants' funds
- have considerable flexibility in the NDIA budget to deal with unexpected operational requirements
- individually ask participants if they would be satisfied with another type of intervention for a short period e.g. osteopathy rather than physiotherapy, and
- have temporary government provision of services as a last resort.

RECOMMENDATIONS

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publishes results allowing providers to plan services

adequately.

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participants to activate the supports funded in their plan.

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competition or an acceptable level of amenity.

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