

Submission for The Department of Social Services and the National Disability Insurance Agency

### NDIS Thin Markets Project

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#### Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

Our core function to is influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e. self-advocate).
- To educate and inform stakeholders (ie: about the needs of people with a physical disability) so they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

#### Introduction:

The Physical Disability Council of NSW (PDCN) appreciates the opportunity to provide feedback to the Department of Social Services and the National Disability Insurance Agency for the NDIS Thin Markets Project. As a peak body representing people with disability, including National Disability Insurance Scheme (NDIS) participants, PDCN will respond to the following targeted questions.

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

As indicated above, PDCN's role in the sector is as the NSW peak body for people with a physical disability, driving systemic change. We provide expert advice, information, and support to our members, the community and to Government, including representation on more than 25 government and sector advisory boards and committees. We undertake policy work that is informed by the views and experiences of our members, whom are people with a physical disability, in order to effect inclusive change across all life domains.

In relation to the NDIS, many of our members have an NDIS plan and contact us when they experience issues or require advice or information. In addition, we hold regular community consultations and conduct educational workshops in Sydney and rural and regional areas of NSW.

In the past we have had also contact with additional NDIS participants through our NDIS Ready Project, which consisted of workshops and individual support planning sessions to assist in

preparing for accessing the NDIS. This project was funded by the NSW Government's Department of Ageing, Disability and Home Care (ADHC). We continue to support our members, and other people with disability who have a NDIS plan, through our NDIS 'Plans in Practice' workshops and individual NDIS support sessions. These workshops are designed for people with disability who currently have a NDIS plan, or family or friends who support a person with a NDIS plan. The workshops assist people to better understand or make use of their NDIS plan, or to prepare for a plan review.

PDCN is also funded by the National Disability Insurance Agency (NDIA) to establish peer support groups for people with disability, facilitated by people with disability. PDCN is currently involved in eleven peer groups across New South Wales and is now also building one on one peer mentoring options. The purpose of these groups is to build individual capacity and confidence, and enhance skills amongst the participants, provide information and develop community connections.

In addition, PDCN administers an information and referral phone line where we take enquiries from the general public, members, community organisations, all levels of Government and other stakeholders.

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

As previously mentioned, PDCN is a systemic advocacy organisation, and as such our primary focus is not individual advocacy, however we do reach NDIS participants in a number of ways.

PDCN holds regular community consultations and small group workshops across the state, including in regional and rural areas. These are an opportunity for PDCN members, stakeholders and other people with disability in the community to discuss the barriers they face in having full and equal participation in the community. NDIS issues, including those resulting from thin markets and difficulty accessing services experienced by scheme participants are frequently raised at these consultations and forums.

In addition, PDCN provides small group workshops and individual NDIS support sessions where NDIS participants are provided one on one support to prepare for a NDIS Review, understand their NDIS plan, make best use of their NDIS plan, and develop the skills to allow them to self manage their plan should they wish to do so.

Evidence from PDCN members suggests that a number of our members are affected by thin markets, particularly with regard to accessing quality services, such as support workers and support coordinators. A number of members have reported finding it difficult to engage "good staff", reporting a significant lack of experienced, reliable staff, particularly in rural and regional areas.

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

PDCN anticipates that our members in regional and rural areas of NSW will experience thin market issues in the future. This includes, but is not limited to, people with disability located in northern NSW, west and far west NSW and the south coast. These areas are affected by significant travel distance and geographically isolated participants.

We also anticipate certain service types will be affected, including support coordination, transport, personal care/assistance with daily activities, social support, access to assistive technology, therapies including occupational therapy, physiotherapy and, exercise physiology. PDCN members have reported difficulty in finding experienced, knowledgeable staff who understand their needs, particularly for support coordination. This in turn restricts their ability to utilise the funds in their NDIS plan and makes it difficult for them to exercise sufficient choice and control.

PDCN believes there will be shortfall in capacity to deliver services to Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) communities., particularly in getting support services with trained personnel whom identify themselves as indigenous or CALD or speak participants' native languages.

Settlement Services International (SSI) reports that people from CALD backgrounds have similar rates of disability to the rest of the population<sup>1</sup>, however in 2018-19, only 9.3% of people accessing the NDIS were reported as being from a CALD background.<sup>2</sup>

Similarly, people who identify as ATSI are twice as likely to experience disability as the rest of the population,<sup>3</sup> however only 5.8% of NDIS participants reported as being ATSI identified.<sup>4</sup> This suggests that both communities are not being reached and engaged in the scheme, and it is likely that thin markets will continue to exist in these communities until they become fully engaged.

Finally, PDCN is aware that the deafblind community are, and will be, affected by thin markets and a shortfall in capacity to deliver services. This is a low income cohort with complex, specialist needs requiring a high level of support, knowledge and information. There needs to be a funding commitment to allow participants who are deafblind to continue to access the supports they need, including the training of additional interpreters. Importantly, a number of services that are relied on by the deafblind, blind or vision impaired, for example library services, accessible formats and help desks, are not covered by individual funding agreements.<sup>5</sup> In addition, people with vision impairment or who are deafblind living in rural or regional communities are at risk of thin markets,

<sup>&</sup>lt;sup>1</sup> Settlement Services International, Mortimer, P., and McMahon, T., 'Still outside the tent: cultural diversity and disability in a time of reform – a rapid review of evidence', October 2018

<sup>&</sup>lt;sup>2</sup> Council of Australian Governments, Disability Reform Council, Quarterly Performance Report, March 2019

<sup>&</sup>lt;sup>3</sup> Australian Bureau of Statistics, Aboriginal and Torres Strait Islander People with a Disability, 2012 (cat. no. 4433.0.55.005)

<sup>&</sup>lt;sup>4</sup> Council of Australian Governments, Disability Reform Council, Quarterly Performance Report, March 2019

<sup>&</sup>lt;sup>5</sup> Vision Australia, Position Paper - Response to Productivity Commission Inquiry into NDIS Costs, July 2017, p.10

as in these areas there is fewer services overall, participants have to travel to access them, and they may not have the specialised knowledge needed to support them.<sup>6</sup>

# 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.)?

In PDCN's experience there are a number of barriers affecting the availability of services and participants' ability to access those services including cost, lack of choice, inadequate training of service providers, funding inadequate to cover associated costs of service provision and no services available. These are consistently reported across both metropolitan and rural and regional areas and across types of services including occupational therapy, physiotherapy, assistive technology, podiatry, exercise physiology, assistance with daily living, social support, community participation, home and garden maintenance and home modifications.

PDCN observed that the choice and control of NDIS participants is being compromised through having insufficient support and information available to implement their NDIS plan. PDCN members have consistently reported an absence of locally available services or their choice limited to only one disability service provider as a significant issue outside of metropolitan areas. Participants in rural and remote NSW have reported difficulty in sourcing suitable support coordinators and skilled workers, restricting the effectiveness and flexibility of their NDIS plans.

Anecdotal evidence from NDIS participants across NSW indicate there is a shortage of skilled, educated and reliable support coordinators and support workers. Participants find that support coordination is only offered by big providers and they aren't doing it well; there is lack of expertise and a lack of flexibility. Participants also report that their support coordinators are not clear about what they are billing for and as a result, participants are not getting the services they need and are not seeing outcomes. Participants also indicated that the process is slow, arduous and unnecessarily bureaucratic. Support coordinators and support workers are not being trained to understand what people with disability are experiencing and can't recognise what their needs are.

PDCN believes there is a significant knowledge deficit amongst disability service providers on how best to support clients on the NDIS, including how best to progress the process, providing accurate advice when forming service agreements, preparing for plan reviews and in the delivery of support coordination to clients. This in itself presents a barrier as participants aren't aware of what is available to them, or what they may be missing out on, and they are not accessing available services, which may lead to providers withdrawing from a market because they believe demand is low. PDCN suggests this is particularly true of CALD and ATSI communities, whose engagement with the NDIS is lower than the rest of the population. This could be due to cultural stigmas preventing people from accessing the scheme, people living in remote locations or simply lack of knowledge and education about the NDIS.

PDCN feels the NDIA price guide for disability support work has significant consequences for the quality of care provided to NDIS participants and creates a thin market, and from this a barrier to

<sup>&</sup>lt;sup>6</sup> Ibid, p.11

accessing services, because workers are unwilling to take on these poorly paid roles. Research conducted by the UNSW Social Policy Research Centre indicates that pricing arrangements are not "fully enabling disability support workers to deliver services which are personalised, coordinated, responsive or safe"<sup>7</sup>.

The current NDIS pricing for disability support work is based on direct hours of support provided to the participant, and does not allow for staff training and development, ongoing supervision and support of workers, staff meetings, care coordination and the completion of administration tasks, all of which are essential for consistency of care. Combined with the increasing casualisation of the disability workforce PDCN believes this is negatively affecting both the quality of services received by NDIS participants and choice and control of NDIS participants.

Another issue identified by PDCN members as affecting participants' ability to utilise their NDIS plan is the associated costs of accessing services, including transport. Transport is a barrier for a number of reasons. Firstly, the funding supports for transport provided by the NDIS in plans are inadequate, do not meet a year's worth of an individual's transport requirements and hence do not promote choice and control for participants. Secondly, for participants who are very isolated, the cost to travel to access services is too high, thereby limiting their choice and control. Thirdly, the cost for providers to deliver services, particularly in remote areas, is also too high and means they are unwilling to travel to do so. In rural and regional areas, participants report travelling up to 6 hours to access services because they cannot find suitable local services, services are unwilling to travel to their location, or the services that are available are not specialist services.

Housing and Specialist Disability Accommodation (SDA) presents another area of concern for PDCN. SDA is a relatively small, specialised and complex part of the scheme. It is for a very small proportion of NDIS participants with very high and/or complex needs, estimated to be 6% of the scheme.<sup>8</sup> However, there is a number of issues faced by providers in the area of disability accommodation, including lack of information about the SDA and how it will operate, supply and demand risks and how to access funding. This uncertainty and lack of clarity around the process then impacts the number of providers participants can choose from because providers aren't willing to enter the market.

### 5. What short-term and long-term approaches do you believe would best address thin market issues for you? Are there approaches you would not support?

One of the main objectives of the NDIS, as set out in the NDIS Act 2013, is "enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery

<sup>&</sup>lt;sup>7</sup> UNSW Social Policy Research Centre, Cortis, N., McDonald, F., Davidson, B., Bentham, E., 'Reasonable, necessary and values: Pricing disability services for quality support and decent jobs', June 2017

<sup>&</sup>lt;sup>8</sup> Achieve Australia, 'The trouble with Specialist Disability Accommodation – let's break it down', Enable Magazine, 2019

https://achieveaustralia.org.au/the-trouble-with-specialist-disability-accommodation/

of their supports"<sup>9</sup>. PDCN would like to see this reflected in how the NDIA address thin markets. PDCN's overarching goal is an equal and inclusive community for all people living with disability in NSW. PDCN supports approaches that put the person and community at the forefront of the solution, and makes the following recommendations:

- The NDIA continue to work in collaboration with Federal, State and Territory governments in implementing the NDIS Market Enablement Framework and ensure market issues are addressed and participant needs are met.
- The NDIA establish a comprehensive information database of services, tools and resources that is assessible, continuously updated and properly funded to ensure the database reflects the regular changes to the NDIS and provider market.
- The NDIA expand the role of support coordinators, provide them with more training and support to better enable them to assist their clients, and ensure support coordination is adequately funded in individual's plans, and available to all participants whom wish to utilise this service. In some areas, and for those with complex needs, this may mean directly providing support coordination services whilst also engaging in education and training for service providers, with the view to leaving the market once there is sufficient supply established.
- The NDIA release more information on supply and demand through market position statements. This would allow providers to position themselves where the need is greatest. The NDIA would need to ensure data is collected regularly and the process is well regulated.
- The NDIA develop and implement comprehensive strategies with measurable outcomes and reporting mechanisms to reach and engage ATSI and CALD communities, remembering that these communities are each unique and it is important to not take a 'one size fits all' approach, ensuring different strategies for each cohort.
- That the NDIA make more adequate provisions, or provide incentives for, the cost of travel in NDIS plans and/or price guidelines. The NDIA must consider the added cost to services when they include substantial travel distances. Service providers have less incentive to enter rural and regional markets if these additional expenses are not fully accounted for in NDIS price guidelines.
- The NDIA consider introducing a Multi-Purpose Service Model (MPSU) in rural, regional or remote communities. This has worked effectively in Victorian health care<sup>10</sup> and could be applied, where necessary, to the NDIS.
- Where there is no other option, leaving it to market forces will result in a market-driven approach (rather than consumer-driven), and may lead to no market whatsoever. In this situation PDCN suggests the NDIA becoming Provider of Last Resort (POLR).

<sup>&</sup>lt;sup>9</sup>Department of Parliamentary Services, 'The National Disability Insurance Scheme: A Quick Guide', Research Paper Series 2016-17

<sup>&</sup>lt;sup>10</sup> Joint Standing Committee on the NDIS, Inquiry into Market Readiness, 2018

PDCN would not support the following:

- Any reduction of funding in participants' NDIS plans that restricts choice and control and may further restrict the market as a consequence.
- The NDIA appointing 'preferred providers', or any change that may mean small businesses cannot compete against large organisations, leading to limited choice and control for participants.