

## **PRODUCTIVITY COMMISSION REVIEW OF NDIS COSTS**

### **Introduction**

Leadership Plus is an advocacy service for people with disability in the state of Victoria, funded through the National Disability Advocacy Program (NDAP). In Victoria there are over thirty disability advocacy agencies funded through the state program and national program. These funding streams are independent of disability service delivery, providing independent disability advocacy.

Currently, it is unclear how Disability Advocacy will be funded and structured post the NDIS roll out. Advocacy is involved in issues relating to human rights and as an example of the advocacy work we do, the top three issues Leadership Plus reports over recent years are:

- Services – service delivery and quality including disability specific agencies and others,
- Finances – including financial management issues with appointed Administrators, capacity to manage personal income, loss (or risk of loss) of funds due to theft or mismanagement by friends or family, and
- Accommodation – for example, having appropriate housing, maintaining tenancy in public and community housing, risk of homelessness, addressing safety concerns

Leadership Plus prioritises people with Acquired Brain Injury, parents with disability and people with disability from CALD backgrounds. We recognise that the community of people with disability is diverse and there is no question that some of the most vulnerable members are those without known and active family members or friends. In regards to the NDIS, we are particularly concerned for those who are dependent upon the disability service structure for all activities of daily living and knowledge of rights. At the pre-planning and planning stage of participation in the NDIS, we consider the assistance of an advocate to be integral to a successful outcome for these vulnerable people.

**We therefore recommend that the Commonwealth ensure the continued funding and expansion of NDAP for both individual and systemic advocacy.**

## **Key challenges for people accessing and participating in the NDIS**

We consider that the NDIS does not sufficiently recognize the complexity of disability and how issues such as homelessness, family violence, alcohol and other drugs and the criminal justice system impact on the lives of people with disability. Gender, ethnicity and class add another overlay to the disadvantage experienced by this group and this has significant implications for their ability to access the scheme.

Leadership Plus is funded to provide advocacy to people with disability from CALD backgrounds in 3 local government areas in the outer metropolitan regions of Melbourne. We have found that there is low awareness of the very existence of the NDIS amongst this cohort, a reluctance to acknowledge disability and therefore low rates of engagement with disability services. Within many CALD communities there is a certain 'shame' attached to disability and the care of disabled family members is considered to be the individual family's responsibility.

**We recommend that the NDIA resource agencies and community organizations to explore ways to engage with CALD communities and to provide information and support to access the NDIS.**

Many current participants in the scheme report to us that the planning process was too rushed and that their planners often had little understanding of the particular support needs relating to their disability. This resulted in inadequate or unsuitable supports being funded. People with complex needs - for example, a person with an Acquired Brain Injury who also experiences episodic mental illness - present particular challenges at both the planning and implementation stages of scheme participation. Planners and support coordinators may not have the necessary knowledge or training to work effectively with this cohort.

**We recommend that assessors, planners and support coordinators have the requisite specialized training and experience when working with people with complex needs.**

If more time is allocated for the planning process and the planner has some knowledge and understanding of the disability of the person they are working with, this will reduce the need for plan reviews which are time and resource intensive.

The review process itself is complex and bureaucratic and we have heard of cases where it can take up to 18 months to be completed. Participants who are implementing their second plan are sometimes still waiting for the review of their first plan to be finalized. **We again emphasize the need for skilled advocacy to assist people through this process.**

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## **Pricing structure and funding model**

We believe that the individualized funding model is problematic. Specialist service organizations and agencies which were previously block-funded face an uncertain future and the knowledge and expertise gained over time in regards to discrete disability types may be lost. For example, the Victorian Slow to Recover program of rehabilitation for people with a catastrophic brain injury is considered to be a global leader in best practice for this cohort; however it seems that this model will be lost with the individualized funding model. Years of specialized knowledge and expertise will be lost and rather than that model being replicated across the country, we see a reduction in the highly specialized understanding of independence and capacity-building of those with significant brain injury.

In terms of the preparedness of the sector to service the expected growth in participants to the scheme, it is our experience that the sector already struggles to recruit and maintain properly qualified staff. This is especially true for clients with complex needs such as behaviors of concern or intensive physical support needs, and problems in recruiting support staff are exacerbated in rural and remote areas. Disability support work can be demanding and difficult, requiring emotional resilience and high level problem-solving, yet it is undervalued and does not offer wages commensurate with the degree of responsibility involved. We believe the current NDIS pricing structure will pressure providers to reduce rates of pay even further and that this will have a negative impact on the recruitment and maintenance of staff. We are also concerned that many of the larger service organizations are casualising their workforce and will be reluctant to accept the more support-intensive clients.

### **Case Study: Adam**

*Adam lives with quadriplegia and requires full support for personal care in his home for 6 hours every day. He has been with the same service provider for almost 20 years, but the agency has merged with a number of other agencies over the last couple of years (in preparation for the NDIS) to become a much larger organization with 900 employees. Adam's needs are high-care but his package is sufficient to fund all the support he requires. Nevertheless, he has been given notice that the service provider will be exiting him from their service. They advise it is because they have been unable to recruit staff to fill vacant shifts in his regular support program and cannot afford to continue to fill these shifts with agency staff (as the extra agency costs are borne by the provider). The management reports that in preparation for the NDIS rollout, they are in the process of casualising their entire workforce as well as rationalizing the relative costs of servicing 'high-care' clients. Because casual staff can choose their hours and the clients they want to work with, there is a risk that workers (and management) will 'cherry pick' the less challenging clients and those requiring specialist or high care will struggle to find support*

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*workers. Adam's current service provider is one of the biggest in the state and if they cannot meet the demand for high-care clients, who can?*

### **Interface between NDIS and mainstream services**

We have found a lack of clarity in relation to what is an NDIS responsibility and what is a mainstream service responsibility, particularly in regards to what is covered by Medicare and what can be funded by the NDIS. We have seen poor collaboration and coordination between the state government's Disability Client Services and the NDIS as the scheme rolls out and insufficient planning for those people with disability who are deemed ineligible for the scheme.

#### **Case study: Patricia:**

*Patricia lives with aphasia as a result of a stroke 4 years ago. Aphasia is a communication disability which impairs both expressive and receptive communication but does not affect cognitive function. Patricia had her advocate accompany her to the planning sessions with the Local Area Coordinator. Patricia currently accesses speech therapy and psychological counselling through allied health care plans with her GP. These therapies are directly related to her disability and assist her to lead an ordinary life. The health care plans provide a limited number of sessions every 12 months and are very piecemeal; for example, Patricia may see a different speech therapist at her local community health centre every time she attends but consistency and building a relationship with the therapist is important to Patricia, and in fact, is far more effective clinically.*

*The planner advised that NDIA would not fund the therapies requested as Patricia was already receiving these through the health system, but that attendant care would be funded to assist Patricia to access the community. Patricia was reluctant to agree to this as she considered that she was independent in accessing the community, she needed ongoing therapies to improve her communication and confidence in participating in the community. Patricia's approved plan's stated supports were 4 hours attendant care per week and did not include any funding for therapies. She estimates that at most, she would use one hour per week of the attendant care provided, and this would be to assist her to make telephone calls. Consequently, much of the funding for her NDIS plan will remain unspent. Patricia and her advocate have requested a Review of a Reviewable Decision and have attached detailed letters of support from her current psychologist and speech therapist. A response has been received from the delegate of the NDIA advising that more information is needed regarding functional goals of each therapy before a decision can be made about whether to review the plan.*

Melanie Muir and Amanda Roe, advocates at Leadership Plus, would welcome the opportunity to further discuss the issues raised in this submission with the Productivity Commission.

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