



## **Productivity Commission Review of National Disability Insurance Scheme (NDIS) Costs**

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## 1. Introduction

The Disability Services Commissioner (DSC) commenced on 1 July 2007 under the Disability Act 2006 (the Act) to improve disability services for people with a disability in Victoria. This independent statutory office works with people with a disability and disability service providers in Victoria to resolve complaints.

Our complaints resolution process is free, confidential and supportive and we encourage and assist the resolution of complaints in a variety of ways including informal approaches to resolution, conciliation processes, or under certain circumstances through investigations. Our person-centred approach aims to achieve improved service outcomes while actively supporting the rights of people with disability to live with dignity and respect.

Our understanding, via the complaints process, of the needs and concerns of Victorians with a disability and their interactions with service providers and the National Disability Insurance Scheme (NDIS, or the scheme) uniquely positions us to comment on the issues detailed within this paper: Scheme costs, Scheme boundaries, Planning processes and Market readiness.

In particular, our interaction with complaints gives us particular insight into the main issues that scheme participants are facing with the implementation and rollout of the NDIS.

## 2. Scheme costs

There are a number of factors that may influence future costs of the NDIS, with one of particular note being the potential growth beyond estimated numbers as traditionally hard-to-reach cohorts possibly move onto the scheme.

Over the ten years of our office, we have recognised that we have very little contact with hard-to-reach cohorts, which may include those from a Culturally and Linguistically Diverse (CALD) background, or those from Aboriginal or Torres Strait Islander backgrounds. In fact, only 1.1 per cent of all complaints received by our office between 2007 and 2016 were from individuals from a CALD background who requested support from a translator.

**Issue: Hard-to-reach cohorts may not have been included in original NDIS estimates.**

*Our office received an out-of-scope complaint from the sister of a young man with a disability. She wanted us to help her gain guardianship for her brother so that she could help him access disability services. Their parents didn't want to put an application in for support, as they had always looked after their son themselves with the help of their local community and didn't trust non-Arabic-speaking carers from outside of the family. We referred her request to the Victorian Civil and Administrative Tribunal and to the Office of the Public Advocate.*

According to a 2009 report, people with disability from CALD backgrounds are largely under-represented within support service systems<sup>1</sup>. They were:

- Four times less likely to receive accommodation support services
- Two and a half times less likely to receive community support services and community access services
- Three times less likely to receive respite services
- Two times less likely to access employment services

The Ethnic Communities Council of Victoria suggested several reasons for this discrepancy in their report *Talking Disability* (May 2014).<sup>2</sup> These included:

- A lack of understanding of a complex service system
- Service models that focus on the individual rather than family and shared care – such as the NDIS
- Information and outreach not reaching culturally diverse communities
- Shame and stigma as significant disincentives to seeking support beyond the family
- Exclusion due to migration status (e.g. permanent residency) and/or competing settlement priorities

The NDIS purports to “give all Australians peace of mind that if their child or loved one is born with or acquires a permanent and significant disability they will get the support they need”. This needs to include hard-to-reach cohorts such as those from CALD backgrounds, regardless of whether it increases future estimated costs of the scheme or not.

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<sup>1</sup> Productivity Commission 2009, Report on Government Services, Chapter 14 Services for people with a disability

<sup>2</sup> Ethnic Communities Council of Victoria 2014, *Talking Disability*

### 3. Scheme boundaries

**Issue: Mainstream health and support services need to be resourced to support pathways to enter the scheme.**

Mainstream services offer an important pathway into the scheme, especially for hard-to-reach cohorts as detailed in previous pages. Our office often receives contact from general practitioners and allied health professionals who play an important role in the lives of people with a disability who may not otherwise know about our service.

*Our office received a letter from a general practitioner, voicing concerns about how one of his patients with a disability was being supported in his group home, as they had missed a number of appointments. The doctor was worried about the level of care staff at the house were providing, and the lack of accountability demonstrated by these missed appointments.*

It is important that the capacity of mainstream services including Commonwealth services such as Centrelink, and State services such as schools, hospitals, general practitioners and allied health professionals are developed via a financial investment, and can be utilised as a source of information, and a referral pathway to the scheme.

**Issue: Established community linkages programs must be strengthened.**

Our office has observed that state based initiatives such as Metro Access, Rural Access and Deaf Access, create important links within communities to support the inclusion of people with disabilities. For many people with disability, their relationship with their local Access worker helps them to connect to local mainstream services such as education, training, sport, recreation, transport and the arts.

Future investment in Information, Linkages and Capacity Building (ILC) and Local Area Coordination (LAC) initiatives would be strengthened by working in partnership and building on the strong community relationships established by these existing programs.

## 4. Planning processes

Our office has received a number of complaints and enquiries about the NDIS planning process from both participants and family members. This feedback and the issues detailed in the complaints received has highlighted a need to strengthen the planning process and, ensure flexibility to meet the needs of the participant in an efficient, robust and transparent manner.

### **Issue: Planners are not providing clear and accessible information about the planning process including when and how planning will take place.**

*A sister of a participant said that someone from NDIA had rang her while she was in the car. They advised that they were 'only collecting answers' and it would 'only take a minute'. Following that conversation, her sister received a plan for approval from the NDIA, with less funds than she had previously received.*

### **Issue: Planners are not clearly identifiable and accountable.**

*A participant told us that the planner got his plan wrong and he couldn't call the planner directly to talk about the issue. He raised further concerns that no one at the NDIA records his calls, so he feels he cannot escalate his complaint, as there is no record of his previous contact.*

### **Issue: Planners are not providing flexible and person-centred planning opportunities, which may include giving participants the option of having planning completed in places they are comfortable with easy access.**

*A family of a young male participant was advised by their planner that it was not normal to have planning completed at the participants home, and that the planning meeting would need to be completed at the local office. The family raised concerns that they did not feel as though they had any choice in the matter, despite the fact that the participant would have been more comfortable and at ease in his own home.*

A reliable, clear and accessible planning process will help to minimise the risk of participants receiving inadequate funding for their needs, or being uncertain about

their options. It will assist in giving participants the choice and control that the scheme promises.

The performance of planners need to be monitored, and participants should be actively solicited for feedback. Feedback and complaints create important learning opportunities for service providers, and planning agencies need to invest in developing strong mechanisms to understand the experience of the people they support. This is about supporting one of the guiding principles of the NDIS – choice and control.

## 5. Market readiness

In 2015-16, 48 per cent of all in-scope enquiries and complaints to DSC were about service quality, with 25 per cent about staff-related issues.

With this in mind, the expected increased numbers of the disability workforce under full roll-out of the NDIS raises concerns about the quality of the supports that will be provided. The probable increased numbers of unqualified staff or unregistered providers providing complex care to people with a disability, including those with complex needs and behaviours of concern, could lead to increased risk of abuse and neglect in the disability sector, especially as unregistered providers will fall outside of the current safeguarding framework..

Our office has already begun to see complaints relating to workforce preparedness and the risk factors associated with un-registered providers.

### **Issue: Service providers have inadequate staffing numbers.**

*A family contacted us because they had concerns that their son could not access supports at his chosen service provider because that service was finding it difficult to employ suitably qualified staff members.*

### **Issue: There are long wait times for accessing services.**

*A mother of a participant called us because she had to stop working in order to support her son in the family home. He was waiting for his behaviour support plan to be completed before he could access the service of his choice.*

**Issue: Participants and families are not aware about how to choose a qualified or registered provider.**

*A mother of a participant contacted us to ask if a certain service provider was registered. She had checked the NDIS website and could not find their name. She was also concerned that there was no minimum qualification for disability workers under the NDIS, and what that meant for choosing providers who were capable of looking after her child's needs.*

When service providers do not have the capacity to provide qualified and appropriate support to meet growing need, participants and families do not have true choice and control. Investment is required to improve individual control over entry to the scheme and the planning process.

**Issue: Protecting the rights of people with severe and profound disabilities.**

There are a number of issues that may affect ensuring the best possible outcomes for people with severe and profound disability, including but not limited to:

1. If family members of a person with a disability choose to self-manage an NDIS plan, what safeguards are in place to protect against abuse?
2. How are staff appropriately trained to manage people who display behaviours of concern in relation to unauthorised restraint?
3. How will design of the scheme ensure the voice of the person with a disability is heard and regarded with prime importance, particularly if the views of their family members are in conflict?
4. How will the free market ensure that people with complex support needs including significant behaviours of concern are provided with high quality services that meet their needs?
5. Will there be a provider of last resort when service providers decline to provide services based on the needs of the person who has a disability or on the perception that their family members will be challenging?

*An elderly parent with an adult son with high support needs contacted our office. He had been using disability services for most of his life, however three agencies had since declined to provide services to him citing lack of appropriate funds and capacity. The parent believed that this denial of service was due to them being considered to be too demanding or challenging, and they were worried about how their son could be appropriately supported.*

The concept of the 'provider of last resort' is problematic. As mentioned earlier – when an NDIS participant and their family do not have the opportunity to select from a larger range of service providers, based on location, availability, or otherwise, they no longer have the choice and control that is often touted as a benefit of the free market NDIS.

## 6. Conclusion

As the body responsible for handling complaints about the Victorian disability services, our office is well aware of the range of issues that many scheme participants and their families are currently facing during the transition to full scheme.

Planning processes during this transition stage has proven to be a particular issue, with participants not being appropriately or adequately supported to participate fully in the planning process. Plans should be owned by the individual with the disability – they should then have input and control of the planning process. Planners need to be person-centred in their approach to planning, including and involving participants at all points of the process.

Our history and experience in handling complaints about services also highlights that there are basic service quality issues that will not be resolved through a change in funding model. Poor quality of services, staff training and knowledge, and issues with service access will continue to be a theme in an NDIS environment unless strategies are put in place to address workforce, accreditation, and quality assurance in the long-term. This will require financial investment.

There is one key question that service providers and Federal and State Governments need to keep in mind: **Is the person with a disability supported in a person-centred manner and given choice and control over their supports?**

From hard-to-reach cohorts of individuals with disability, to long-term recipients of disability services, to those with complex communication needs – all Australians with a disability have a right to access the support that they need. The National Disability Insurance Scheme makes that promise, and our current and future systems and agencies have the responsibility of ensuring that this promise is fulfilled.