

**Submission  
No 200**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL  
DISABILITY INSURANCE SCHEME AND THE PROVISION  
OF DISABILITY SERVICES IN NEW SOUTH WALES**

**Organisation:** Australian Association of Developmental Disability Medicine Inc.  
**Date Received:** 8 August 2018

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# AADDM

Australian Association of  
Developmental Disability Medicine

## **Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales. August 2018.**

### **August 2018**

The Australian Association of Developmental Disability Medicine (AADDM) is an organisation of medical practitioners who specialise or have an interest in the health of the over 300,000 Australian children, adolescents and adults with intellectual disability (ID). The key aim of AADDM is to improve the health of children, adolescents and adults with intellectual and developmental disability.

We appreciate the opportunity to provide feedback on the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in NSW. AADDM supports in principle a person centred model of disability service provision and funding that is adaptable to the person's, and their family's, needs and is effective in facilitating inclusion in the community. We recognise that disability services may also fulfill a therapeutic role designed to effect improvements in the future in one or more key areas and so must be evidence based. The needs of the family in particular need to be considered as they typically provide more extensive and sustained care for the person with a disability that in the general community.

However, we have significant concerns about our early experiences of the NDIS implementation, notwithstanding some positive experiences of both plans and the planning/eligibility processes. The commitment and expertise of many in the disability sector is acknowledged, but major systemic issues are impacting the experiences of people and their families and challenging those of us in other sectors who are supporting them in other ways.

*"We moved back to Australia because we thought the system would be more helpful than in Italy, but we made the wrong decision, I should have stayed with my family and the therapy systems there", Father discussing services with me on the phone. His child has autism and global delay, and remains on an ECEI waitlist.*

1. Despite the potential for the NDIS to positively transform the disability sector, it has introduced onerous bureaucracy, lengthy delays, fragmentation of services, and unpredictability of services meeting needs. Patches to the system attempting to improve the delivery and coordination of care only lead to confusion and frustration for those of us making referrals or providing other supports.

*"Can you just please let me know what I need to do", parent emailing following confusion expressed about service options.*

2. The needs of people with complex needs may not be met due to inappropriate funding plans, lengthy delays for a review of the existing plan or inexperienced professionals

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providing services. This is particularly the case for people with developmental disabilities and challenging behaviour whose needs are poorly understood, and if not met, can present risk of loss of placement and risk of harm to the person and those around them. Inclusion in mainstream environments doesn't suit all people, and may present unacceptable risks to safety.

*"They don't get it, we lost respite services and now they won't fund specialist school holiday programs. She can't be at mainstream, others get mainstream", Mother describing the loss of funded programs and inadequate funds within the NDIS plan to cover school holidays. Her daughter has a severe-profound intellectual disability and autism.*

3. Coordination across sectors has become almost impossible due to the plethora of professionals and providers, who have limited funds which do not include expectations or allowances for activities to achieve collaboration. For people with complex needs, it is necessary for each involved professional to liaise with other services, as siloed services are unlikely to provide any significant benefit. One of members was told by the service coordinator that she worked in health, and NDIS didn't cover that, resulting in a complete breakdown between the health and disability sector that didn't exist before.
4. NDIS needs to acknowledge that there are many people (health professionals) whose work load has substantially increased to take on the unfunded position to assist parents and carers to navigate and explain the NDIS process. For recipients of NDIS who are managed by non government organisations (NGOs) solely as they have limited capacity or elderly, culturally and linguistically diverse (CALD) parents. AADDM has members who are GPs visiting PWID in group homes, who are increasingly concerned about the integrity, expertise of the information they are receiving and the care they are providing, audit and review of these services are important. Many of these organizations also bundle other services such as physiotherapy, OT and some are hiring inadequately trained or experienced staff to provide care to these vulnerable people when previously these professionals are highly skilled individual employed by health.

*"Thank you for your email and for listening to me on Friday, I really appreciate it. Once I get a couple of reports ... I will chase up NDIS and/or Lifestart - thank you for putting him on the wait list", a parent who was highly anxious and upset, not understanding why her son couldn't get funding, and not understanding the process.*

5. Extremely lengthy delays have been created, that didn't exist in the past, by the bureaucracy of determining eligibility, allocating planners and creating a plan. This entrenches disadvantage as those able to pay are more likely to maintain intervention and educational services for their child, whereas those with fewer financial, personal and social resources are less likely to be able to resource their child.
6. It appears in some of our members' experience, that these plans are very much dependent on the interest and quality of the individual planners, some are very knowledgeable about the disability sector whereas others are not. Some people are also offered telephone interviews and these have been disappointing outcomes because the parent or carer wasn't

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given the option of a face to face planning meeting or to have another person or advocate present, which presents significant difficulties as the goals were not properly considered and some aspects of the care required were not explained or given the appropriate emphasis and not approved or left out. However inconsistencies with planners were stark. One example for a family where a brother and sister both with similar problems of developmental disability goes to same day program, one was approved for 4 days , the other was only approved for 2 days. GPs are seeing many examples of these inconsistencies.

7. Lengthy delays with getting reports to substantiate need, e.g. OT and functional assessments by psychologist for challenging behaviors often are not funded or cant be afforded by applicants/parents or carers, etc but required to assist in the application process to address the needs of the PWID particularly the complex patient with challenging behaviours and Intellectual disability with coexisting mental health conditions.

*“So there’s nothing, I can’t see community health anymore. I don’t have money!”, Mother discussed her worries about the loss of services whilst waiting for the ECEI.*

## Key Issues

1. **Loss of sector leadership (training, safety, links and fostering of academic collaborations)- which will see erosion of sophistication**
2. **Loss of leadership in interagency collaboration- which cant easily be re-established with multiple NGO partners and required government leadership**
3. **Loss of sophistication and availability of behavior support**
4. **Lack of adequate funding model and pathways for people with complex needs**

## Recommendations

1. Ensure all plans for those identified to have complex disabilities include funding for interagency collaboration. This may be for personal face to face meetings, provision of report or training. In the application and reapplication for NDIS planning, there should mandated direct engagement with all individuals and agencies involved in support of the person, so that all have input into the articulation of needs in the funding application.
2. Review and address systemic issues that have resulted in onerous bureaucracy, especially at the point of first contact.
3. Planners need in-depth training in disability, especially in the needs of people with complex disability and high support needs, including challenging behaviour.

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4. Introduce a fast track, approval in principle, for people with severe and complex challenging behaviours, or other psychosocial risk factors, such as child at risk of significant harm, or ageing parents of adults who can no longer support them or where needs suddenly fluctuate. We have had instances where families have been in crisis, but have to wait their turn to determine eligibility.
5. Ensure plans are effectively and directly, with consent, communicated with key stakeholders such as paediatricians, psychiatrists, rehabilitation physicians or general practitioners.
6. Remove any government policy that excludes a person from receiving services merely on the basis of a diagnosis in absence of alternative service provision.
7. Build in “top up” services during periods of transition, such as to school or leaving school.
8. Review the effectiveness of the services the person is actually receiving against international benchmarks and person centred outcomes.
9. Include determinants of interagency collaboration in outcome measures for the NDIS.
10. Ensure family needs are identified in any planning process.
11. Introduce assessments of carer stress, as the person’s application makes its way through the eligibility and planning processes and with time build in improved mechanisms to support carers in this process- so there is continuous improvement. The NSW state government should take some responsibility in providing an avenue of last resort (even if temporarily) for those deemed ineligible, are in crisis or are facing lengthy delays. Please don’t hesitate to contact us if we can assist further.

Yours sincerely

Dr Jacqueline Small

Developmental Paediatrician, President, and

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