



**SUBMISSION**

**The National Disability Insurance Scheme  
Bill 2012**

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## Executive Summary

Ai-Media was founded in 2003 as a social enterprise dedicated to ending the experience of exclusion that people with disability face, and has been a long-time advocate for the NDIS.

Our prior contributions to the Productivity Commission reviews and NDIS-related consultations (submissions and testimony) are referenced on our website.<sup>1</sup>

We thank the Government and the Senate Standing Committee on Community Affairs for the opportunity to comment on what promises to be transformational, albeit long-overdue, legislation for millions of Australians affected by disability, and everyone at risk of acquiring disability.

- First and foremost we congratulate the Government on this bill, and hope that the NDIS becomes a reality by March 2013.
- We welcome the overall structure of the legislation as appropriate, given plans to review and refine over coming years, and look forward to the ability to comment on the relevant regulations and amendments in due course.
- We make some further comments and recommendations in the remainder of this submission around governance arrangements, range of supports, diagnoses, accessibility and eligibility.

We look forward to contributing further to this submission in verbal testimony to the Senate Committee.

## 1. Let's Get Started

Australia's legacy disability non-system has been a disgrace for decades. In 2009 the shocking state of affairs was laid bare in the **Shut Out** report, following a consultation initiated by the Government in 2008:

“Until the concept of disability disappears and is replaced by a society that is structured to support everyone’s life relatedness and contribution—until that day my life and opportunities and the lives of every other person who carries the label ‘disabled’ depends on the goodwill of people in the human service system. Goodwill is no substitute for freedom.”<sup>2</sup>

The unnecessary human pain and anguish caused by the lottery of coverage and support was exacerbated by outdated social attitudes lingering from a time when people with disability were excluded from the rest of society.

“It is not unusual for people to be left to sleep in their

<sup>1</sup> <http://www.ai-media.tv/About/Ai-Media-policy-positions>

<sup>2</sup> Submission quoted in National People with Disabilities and Carer Council, Commonwealth of Australia (2009) *Shut Out: The Experience of People with Disabilities and their Families in Australia*, National Disability Consultation Report [http://www.fahcsia.gov.au/sites/default/files/documents/05\\_2012/nds\\_report.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/05_2012/nds_report.pdf), p 1.

wheelchairs through lack of care hours to get them to bed, or for them to be left without a meal as there is no-one who can prepare it for them.”<sup>3</sup>

“Another problem with state funding is that a person with a disability can’t move from one state to another without experiencing great difficulties. Our son would like to move north but because he is funded by another state this is almost impossible. We approached the authorities and were told that he could apply but would not be considered until he actually lived in the specific state. Even though his funding would be transferred across to his new state, it only lasts one year and then reassessment would occur, leaving us wondering what that would lead to, all in all it is far too difficult and risky for him to move.”<sup>4</sup>

“If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses, and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have Spina Bifida.”<sup>5</sup>

Australia’s ratification of the UN Convention on the Rights of Persons with Disabilities (UN Disability Convention) in 2008 created a legal obligation to match the moral imperative of disability reform.

The economic imperative was added with the Productivity Commission Report (PC Report) in 2011<sup>6</sup>, as summarised in the first two paragraphs of the Executive Summary:

“The current disability support system is underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community. People with disabilities, their carers, service providers, workers in the industry and governments all want change.

Most people know little about Australia’s current disability system and do not know how poorly they would be served were they to need it — this is a system marked by invisible deprivation and lost opportunities. Yet major disability can happen to anyone and at anytime — a simple fall can lead to quadriplegia, and an illness to severe brain damage. Most families and individuals cannot adequately prepare for the large costs of lifetime care and support. The costs of lifetime care and support can be so high that the risks and costs need to be pooled.”<sup>7</sup>

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<sup>3</sup> Ibid, p 20.

<sup>4</sup> Ibid, p 21.

<sup>5</sup> Ibid, p 12.

<sup>6</sup> Productivity Commission 2011, *Disability Care and Support*, Report no. 54, Canberra.

[http://www.pc.gov.au/data/assets/pdf\\_file/0011/111404/disability-support-executive-summary.pdf](http://www.pc.gov.au/data/assets/pdf_file/0011/111404/disability-support-executive-summary.pdf)

<sup>7</sup> PC Report Ibid, p 3.

Some have complained over the last five years that progress towards the NDIS was too slow. Ai-Media maintains that the size and scale of this reform demands sufficient time to ensure it is done right. Ai-Media has also called for early pilots and trials, from which innovations can guide and support the continual improvement of the system. We welcomed the announcement of launch sites effective 1 July 2013 and the Government's commitment to fund the NDIS in the 2013 Federal Budget Forward Estimates.

Ai-Media recommends that, subject to relatively minor modifications, this NDIS Bill be enacted as soon as practicable. This Bill presents a coherent framework for an enduring national system, while retaining flexibility around key issues where further data and negotiation must inform policy and where further community consultation is required.

## **2. Architecture supported**

Ai-Media supports the overall architecture of the Bill, including leaving much of the detail to the disallowable instruments (Regulations). Likewise, we recommend further concise consultation periods prior to publication of Regulations.

While we believe the following comments could improve the legislation and its implementation, we acknowledge that the imperative to transform the current non-system overrides these relatively minor concerns.

## **3. Further suggestions**

### **a) Range of supports**

Choice, flexibility and individual decision-making must be at the core of the Regulations. The range of supports to be funded must be broad, and reflect the priorities of people with disability, their families and carers.

### **b) Governance of the NDIS**

We believe it is vital that the implementation and administration of the NDIS include qualified people with disability, of which there are many. We note and support the inclusion of Section 127(2)(a) in which experience of disability is a qualifying criterion for membership on the Board of the Agency.

It has been submitted by others that the legislation should propose a minimum number of Board members with disclosed disability (some have argued this as a means of ensuring the injustices of the past perpetuated against people with disability by the majority cannot be repeated). Arguments against this "quota" position include that doing so would create two classes of directors, that people with disability must be considered on their own merits, and that such a requirement may create an implication of different constituencies to whom different members of this statutory Board be accountable. We note the competing perspectives and urge the Government to ensure that people with disability are, as a matter of fact, included at all relevant levels, including the Board

of the Agency, its management and staff. We note Article 27 of the UN Disability Convention.

Given the proposed structure of the Advisory Council, Ai-Media recommends increasing the number of representatives of people with disability to six (from four) in Section 147(5)(b)(i). It is recommended that the disability status be disclosed and reported to the general public for both the membership of the Board and the Advisory Council, and to present in the NDIS Annual Report a percentage of people with disability employed within the Agency workforce.

#### **c) Compensation payments**

Ai-Media appreciates that the financial integrity of the NDIS requires not incentivising people away from areas now well-covered by private insurance, and the inherent difficulty of this task. However Ai-Media is not convinced that requiring Participants to take action to obtain compensation (Section 104-105) is the best approach. Another approach would be for the Participant to assign their external rights of recovery to the CEO as a condition of coverage.

#### **d) Interplay with other systems**

Ai-Media notes that in order to deliver on the promise of the NDIS as a national lifetime care and support scheme, the interplay between other government departments including aged care, mental health, education, employment, family and community service, indigenous affairs and veterans affairs, at a Federal and State/Territory level will be critical to avoid repeating the 'confusopoly' of fragmented supports people with disability currently experience.<sup>8</sup>

#### **e) Accessibility**

NDIS information and services need to be accessible for those with hearing loss. Service provision must include funding for live captioning or sign language interpreters. Materials produced by the Agency should be accessible in easy English and Auslan formats.

#### **f) Diagnosis & Eligibility**

Where practicable, Participants should be involved in a diagnosis process once and have an "NDIS Card" to identify their status and eligibility.

#### **g) Developmental delay and early intervention**

The current definition of developmental delay in Part 4 puts an upper age limit of age 6 for a developmental delay diagnosis. This should be made more flexible where a developmental delay diagnosis is delayed through no fault of the Participant. We note that early intervention does not necessarily mean an intervention during early childhood years. The focus should be on early intervention following diagnosis.

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<sup>8</sup> PC Report Ibid, p. 7. See also Ai-Media's Submission on Eligibility and Reasonable and Necessary Supports (NDIS), September 2012, <http://www.ai-media.tv/About/Ai-Media-policy-positions>

## **Conclusion**

Ai-Media is looking forward to the adoption of this Bill in March 2013 by the Australian Parliament and learning from the experiences in the launch sites. The NDIS promises to deliver people with disability in Australia a fair go, and to deliver significant and enduring social and economic benefits for the entire nation.