



# Submission on the National Disability Insurance Scheme Bill 2012

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## 1. Introduction

Nulsen is pleased to have the opportunity to make comment on the National Disability Insurance Scheme (NDIS) Bill 2012 that is currently before the Federal Parliament. We believe that the introduction of this Legislation is an important opportunity for people with disabilities, particularly people with profound and severe intellectual and multiple physical disabilities that are the most vulnerable in any service system. Importantly, the Legislation must ensure that it provides people with disabilities, their families/carers with certainty and hope and those requiring long term/life long care and support are not unduly required to justify their ongoing support needs. In order to ensure certainty and hope, and to safeguard care and support to people with high and complex support needs, the Legislation will require additional amendments in our view.

Our submission is predicated on the view that people with this level of disability have not been well represented in the development of the Bill and that some aspects of the Bill will present certain difficulties to individuals with severe and profound intellectual disabilities and their families. Further, we believe that the implementation of this Legislation should be via a Federated system in ensuring that planning, design and delivery remains locally within the jurisdiction and where appropriate build on the existing systems and infrastructure. In the case of Western Australia, the service system and infrastructure has been built up by people with disabilities, Non Government Organisation (NGO) providers, and the State Government over the past three decades and has the capacity to manage and deliver on a National Disability Insurance Scheme.

The use of the term "*Launch*" is inconsistent throughout this Bill and we would recommend that the title of the Act reflect the reference to the Launch. E.g. *National Disability Insurance Scheme Launch Bill 2012*.

In shaping our commentary, we note to the Senate Committee that whilst the Legislation seeks to provide the legal framework in which to operate a National Disability Insurance Scheme, commenting on such Legislation without knowledge of the Rules that will operationalise the NDIS is problematic and of concern to us. We trust that the Federal Parliament will in good faith ensure that there is significant engagement of people with disabilities, their families and carers and service providers to ensure that the rules align with the intent of the Productivity Commission report into the development of NDIS.

The NDIS represents monumental change for this sector and for people

with disabilities, their families and carers and as such needs to be implemented with caution and engagement of all key stakeholders. It will be critical, above all else to ensure that where good quality and responsive services are provided to people with disabilities within the current systems, and where people with disabilities are satisfied with the services they are receiving, that there is not undue disruption or uncertainty brought into their lives.

## 2. Background

Nulsen was established by parents in the early 1950's to support people then labelled as "Mentally Incurable Children" as this group was not supported well by the government system of the day. Other community groups established in Western Australia at that time viewed people with this level and complexity of disability as 'too difficult'. Hence the establishment of the Mentally Incurable Children's Association now known as Nulsen which has been operating for approximately 58 years. Nulsen provides lifelong care and support via a range of services to people with complex health or challenging behaviour needs. The organisation provides assurance to ageing families and carers who are for the first time witnessing their children's generation outlive them.

Our mission is to enable people with disabilities to live a fulfilling life as part of an accepting community.

To help achieve this we provide a comprehensive range of disability support services including:

- Disability support accommodation with 24-hour assistance so people with profound disabilities receive quality care in a home environment.
- Clinical and nursing support.
- Tailored personal programs for each of the people we support based on their goals, hopes and dreams so they have the highest possible quality of life.
- Creativity programs to foster the spirit and dreams of the people we support.
- Alternatives to employment so the people we support lead more interesting and diverse lives.
- Supporting research to improve the quality of life for people with disabilities.
- Community education for schools and community groups to raise awareness of disabilities and to create an accepting community in which people with disabilities can live.

## 3. Commentary

### **Chapter 3 – Participants and their plans:**

#### **Part 1 – Becoming a participant**

##### **23 (3) When a person meets the Access Criteria**

**Response:** The Association believes strongly that this clause is unfair to people with disabilities in that there is no responsibility on the Agency to ensure it responds to *Access Requests* submitted by a person with a disability. Further, to not respond with a reason in any way to a person with a disability would be in our view contrary to the Principles of the NDIS Bill and the National Disability Services Act in treating people with dignity and respect. To place the onus on the person to re-apply fails to recognise the difficulties some people will face in making one Access Request, let alone repeated.

We are also concerned that such a provision will result in the provision of unrealistic data on applications and demand for services given that the Agency will not be required to maintain a decision waitlist.

##### **26 – Requests that the CEO may make**

###### **26 (1) (a)**

**Response:** We believe that the term “*another person*” is too broad and should be defined. Further, the definition should also make provision for a service provider, (if engaged in an intermediary position by the person with a disability) to be identified as suitable for the provision of reasonable and necessary information.

###### **26 (1) (b)**

**Response:** The undertaking of such reviews and assessments can be costly for the individual. The Act should make provision for these costs to be claimed back as part of the application process to the Agency given that the requests for further assessment is made by the CEO.

##### **29 – When a person ceases to become a participant**

###### **29 (1)**

**Response:** We believe that this section does not align with the recommendation 3.5 of the Productivity Commission Report “*Disability Care and Support*” in which provision was recommended that a person upon reaching the pension age (and at any time thereafter), the person

with the disability should be given the option of continuing to use NDIS provided and managed supports or move to the aged care system. By providing people with the choice to select the most appropriate supports that best suit their needs, an important safeguard to their ongoing care and wellbeing is maintained. Further, the use of terms such as “at least 65 years” is ambiguous and will be cause of confusion to some people with disabilities.

## **Part 2 – Participants’ plans**

### **Division 2 – Preparing participants’ plans**

#### **33 Matters that must be included in a participant’s plan**

##### **33 (4)**

**Response:** The Association is concerned that there is no timeframe established for the approval of the *Statement of Participants’ Supports*. Without this stipulated, we are concerned that a person’s package of supports will be unduly delayed. The approval of *Statements of Supports* and the timely provision of packages should be a priority of the Agency and an important Key Performance Indicator of the agency.

It is also not clear within the Legislation, and this section, as to how emergency and crisis situations will be managed. This matter needs to be dealt with in the Legislation as in many cases of crisis, a provider may be asked or required to respond to a support need. There needs to be provision for the waiver of *Statements of Support* until such time as the immediate emergency care and support arrangements are resolved. The need for immediate management and response to emergency situation should be explicit in the Legislation.

#### **34 Reasonable and Necessary Supports**

**Response:** In this section there is lack of clarity around terms such as “reasonable and necessary supports” and “value for money”. Of concern is who will make these decision and on what basis and what appeals process exist for the applicant. In cases where individuals current care packages exceed the standard funding parameters due to the extreme complexity of the support needs, how will these situations be managed? The Ruled will need to be specific in this regard.

##### **34 (e)**

**Response:** This is an ambiguous clause and one that leaves families and carers particularly vulnerable to having to provide the care and support to

an individual. We do not believe it takes into account the vulnerability and hardships of families and carers e.g. a single mother who may have three children of which one has a severe and profound disability. Our experience has shown the extent to which the other siblings are disadvantaged by the mother having to provide significant level of care to the person with a disability. Nor is there any safeguard provision to ensure that the value of the package is not diminished over time and the family/carer unreasonably has to provide more of the care and support. How 'reasonable' is determined is our main concern.

### **Division 3 – Managing the funding for supports under participants' plans**

#### **43 – Choice for the participant in relation to plan management**

##### **43 (1)**

**Response:** A person with a disability should be afforded full choice in relation to whom they choose to design, manage and deliver on their plan. The Productivity Commission identified that under the NDIS, people with disability would have much more choice in the NDIS, based on their needs assessment and their individualised support package. They could ask a disability support organisation to be the intermediary to assemble and manage the best package on their behalf.

The success of many services provided to people with a disability is due to the building of relationships and engagement between provider and consumer. People with disabilities and their families want certainty and hope and it is with this in mind that we believe that the Legislation should be more specific in noting that a service provider could also be appointed as the plan management provider where requested by the participant.

#### **45 – Payment of NDIS amounts**

##### **45 (1)**

**Response:** The legislation does not address the issue of indexation on individual packages. Indexation is a mechanism currently used in Western Australia to ensure that individual funded packages maintain their value. It is not feasible in our view for an individual who has extremely high ongoing and consistent needs for support, to continually re-submit their plan as an alternative mechanism for maintaining package value given the pressures around wages, cost of living and service delivery. The use of ad-hoc market reviews will also be an inadequate mechanism. The Rules or Legislation should make provision for an indexation mechanism as a tried and tested mechanism for maintaining package value.

## **48 – Review of participants’ plans**

### **48 (1) (2)**

**Response:** Again we believe that the inaction of the CEO in undertaking the review is not satisfactory. The CEO should be required under the Legislation to review the merits of the review and then notify the applicant who may then lodge an appeal against that decision if they deem that necessary.

## **Chapter 4 – Administration**

### **Part 3 – Registered Providers of Supports**

#### **73 National Disability Insurance Scheme rules for registered providers of supports**

##### **73 (1)**

**Response:** We believe that in relation to (c) [qualifications of persons or entities or employees of persons or entities] the term ‘experience’ should also be included as many competent people working within the disability system who may not have formal qualifications but have many years of valuable and essential experience. The inclusion of qualification as the only criteria may have unintended workforce consequences for the sector if industrial instruments for example are tied to such qualifications potentially restricting flexibility, innovation and impacting on cost of labour.

The Rules will need to outline the decision making process or situation which may warrant such prescribed criteria being applied.

### **Part 5 - Nominees**

**Response:** There is no criteria regarding the selection of Nominees nor is there provision to enable the appointment of nominees to be challenged by interested parties, especially when concerns may exist about the current and ongoing personal health and social wellbeing of a participant.

## **Chapter 6 – National Disability Insurance Scheme Launch Transition Agency**

### **Part 2 – Board of the Agency, Part 3 Advisory Council**

#### **127, 147 - Appointment of members**

**Response:** The Association is concerned that there is not adequate provision to ensure equitable representation from different States under the current clause. A State could find that they are not represented on either the Board or Advisory Council.

We believe that States should have the right to appoint their representative, that each State should have at least one representative and that the powers of the other States by majority to veto a State representative by majority vote be removed.

### **Part 5 – Legislative instruments**

#### **209 The National Disability Insurance Scheme Rules**

**Response:** We believe that at a minimum Categories C and D should be incorporated into Categories A and B or deleted.