

This document was prepared by a coalition of Australian disability service providers, including Yooralla, The Spastic Centre and Disability Services Australia.

- It's time to cement a National Disability Insurance Scheme as a central plank of Australia's social and economic policy framework.

A National Disability Insurance Scheme

- It's time to change the way services for people with disabilities are funded and structured in Australia.
- It's time to make services for people with disabilities and their families effective, equitable and efficient.
- Almost every Australian has cared, or is caring, for a family member with a disability, or knows of a family doing so. Many of these families fall through a huge gap in Australia's social services network.
- Those who acquire a disability through a workplace or a motor vehicle accident generally receive financial support. However, for those who acquire permanent disabilities in other accidents, are born with a permanent disability, acquire a permanent disability through a medical condition or have a permanent mental illness, there is no automatic support to meet their needs.
- This is a national disgrace and an issue for every Australian.
- It's time to introduce a new national safety net, ensuring peace of mind for all Australians should they or someone they love become severely disabled.
- In place of Australia's current crisis-driven, outmoded welfare-based approach to disability services, it's time for a modern, forward-thinking National Disability Insurance Scheme.
- Governments are already spending billions of dollars on disability services. A national insurance approach with its inbuilt focus on lifetime needs and claims management would be much more effective and efficient, as well as fair.
- With the number of Australians with a severe physical, intellectual and/or behavioural disability increasing, and the community's capacity to provide informal care declining, it's time to start planning properly for the future, as Australia did in the 1980s when compulsory superannuation was introduced.

The Plan

A National Disability Insurance Scheme (NDIS) would replace Australia's current crisis-driven, welfare-based approach to disability services. The scheme would provide funding for essential care, support, therapy, aids, equipment, home modifications and access to the community, education and training.

As an insurance-based scheme, providing cover to Australians as and when they needed it, an NDIS would be funded by all taxpayers through general revenue or an extension of the Medicare insurance levy. An insurance-based approach to disability services stems from the view that disability is a 'risk' that can strike anyone in our society, with potentially catastrophic consequences if proper support services are not in place, but will not affect everyone.

Because an NDIS would be a major social and economic reform, on a par with the introduction of Medicare and compulsory superannuation, the first necessary step towards implementation is a detailed feasibility study that would allow for careful, thorough planning and consultations with the States and all stakeholders.

It is envisaged that principal beneficiaries would be those Australians with profound and severe disabilities (approx 700,000) who need assistance with daily living tasks (self care, communication and mobility) while people with more moderate disabilities could also be eligible for some assistance based on their lesser needs.

The defining criteria should be needs, as determined by clear eligibility criteria, which would include measures of physical, intellectual and behavioural disabilities.

An NDIS would enable Australia to satisfy the UN Convention on the Rights of Persons with Disabilities, to which Australia became a signatory in July 2008. Today, responsibility for meeting these basic standards is being shuffled between the Commonwealth and the States.

Under an NDIS, people with disabilities would be at the centre of a new service delivery system which would empower them to make choices. Case management would be available for those needing support when

making decisions, meaning that a consumer-oriented market place for services would almost certainly develop.

Services would be carefully planned well in advance rather than crisis-driven, and the current inefficient and inequitable queues for services - a very crude form of rationing - should disappear.

Services would also become more effective and efficient as an NDIS would also aim for continuous improvement.

Service standards and eligibility criteria would be national which would be equitable and enable people with disabilities and their families to move between States or from one local government area to another. This is often very difficult today because support and services are not easily transferable.

Families would be nurtured and supported in their caring roles through respite and counselling, rather than burnt out. Under an NDIS, family carers would be expected to provide age-appropriate care, while also being recognised as a scarce and valuable resource who should be nurtured, supported and given choices in their roles.

Current arrangements for supporting people with disabilities entwine their lives and the lives of their families too closely. In many cases, families have no choice but to keep providing care and support until they become emotionally, physically, mentally and financially burnt out.

Ensuring better support carers through an NDIS is therefore essential, creating new choices and opportunities for them.

An NDIS would also seek to minimise the costs of assisting people with disabilities over their lives, rather than at a particular point in time, by providing - to give a prime example - well-funded and timely early intervention services. Today, effective early intervention is often under-resourced. Under an NDIS it would receive a much higher priority.

An NDIS would also recognise that people with disabilities have changing needs over their lifetimes. Informal family care and support may be desirable and available at some stages in the lives of people with disabilities, but not at all times and so there may be a need for personalised case management.

The supports and services for people with disabilities under an NDIS and the provision of health and education needs would require close co-ordination. This is one of the issues which should be carefully examined as part of a detailed feasibility study.

For example, preventative medical and health practices may be delivered as part of health services or disability services. In terms of education, an NDIS would assist children with disabilities to access the curriculum, including provision of therapy services. However, in a well designed, person-centred system, these bureaucratic distinctions should not matter.

The Feasibility Study should also examine the eligibility criteria. This would include the suggestion that the scheme should apply to people who acquire a disability before the age of 65 and examine how best to ensure that the benefits provided to people who acquire disabilities either just before or just after any age cut off are as similar as possible.

The proposed NDIS would cover all disabilities, including those due to a catastrophic injury - and so, as part of its introduction, there would need to be reforms to current catastrophic injury arrangements. This is because the states, which are responsible for accident compensation, have developed different compensation laws and scheme structures. National coordination is therefore required to better align current motor vehicle schemes, and in particular to introduce no-fault third party motor vehicle accident compensation schemes in Queensland, South Australia and Western Australia.

There is also a need for existing state-based compensation schemes to be broadened to include lifetime care for all people catastrophically injured, whatever the cause. This would remove the many anomalies, inconsistencies and injustices that now exist in disability service provision. A person left severely brain damaged or quadriplegic after falling off a skateboard, for example, or a horse, currently receives no particular assistance, while a person left severely brain damaged or quadriplegic after falling off a ladder at work, or crashing a car, does.

An NDIS would also drive efficiency and best practice across the disability sector. Services would be person centred and individualised funding choices would create a market place for services.

By assisting people with a disability solely on the basis of need and not cause or the type of disability, in accordance with uniform, national guidelines and rules, an NDIS would be the fairest, most efficient and most equitable way to reform Australia's failing disability system.

Key features of an NDIS

Eligibility

- Principal beneficiaries would be people with profound and severe disabilities (in Australia, approximately 700,000 people) who need assistance with daily living tasks (self care, communication and mobility) while people with more moderate disabilities could also be eligible for some assistance based on their lesser needs.
- People with permanent disabilities acquired before age 65 would be eligible for life, without reference to cause and treated equally based on needs.
- People born with a disability or who acquire a permanent disability through an accident, injury or as a result of a medical condition, including mental illness, would be eligible.
- No fault; the provision of support and care for people with disabilities would be separated from legal action for negligence/culpable behaviour.

Benefits for people with disabilities

- Care, support, therapy, access (although not income support or housing), based on functional impairment.
- Person-centred services and support based on the needs and choices of each person with a disability and their family.
- Case management to facilitate independence, maximise potential and plan transitions over the life course, when required.
- Early intervention a top priority.
- Aids, equipment and home modification needs met on a timely basis.
- Training, development and access to work to build self-esteem and reduce long term costs.
- New competitive market place for service provision likely to develop, helping to drive efficiency and innovation.

Benefits for families/carers

- Families expected to fulfill normal age-appropriate caring roles.
- Tailored support for carers, through respite, information, counselling, training and education based on family structure and disability.
- Families able to choose to work or provide informal care, as for families without disabled members.
- Part-time work and labour force engagement facilitated.

Governance and scheme management

- Pooling of individual risks.
- Mix of Commonwealth and state schemes (including catastrophic injury schemes) with Commonwealth coordination to ensure a consistent national framework.
- Coordinated approach to funding, including Commonwealth, states and territories
- National standards of assessment, care, support and case management
- Governance framework to manage scheme assets, liabilities and data collections to optimise scheme performance and monitor usage.
- Active claims management.
- Independent review/appeals process.

Other features

- Better coordination with aged care, health, education, housing and other sectors.

Research into best practice and prevention strategies to drive effectiveness, efficiency and to reduce long term costs, as happens now, for example, with the Victorian Transport Accident Commission.

The Economic, Social and Inter-generational Arguments for an NDIS

The cost of caring for people with disabilities now represents a very large unfunded liability. It must be met directly by families, friends or the community through government expenditures.

In the next 15 to 20 years, the size of this unfunded liability will grow significantly due to increasing incidence of disability at birth ¹ (older mothers, IVF and increased survival rates amongst very low birth-weight babies), increasing numbers of people with acquired brain injuries, people with disabilities living longer and others acquiring disabilities as they grow older. Based on population projections, Australia's population will increase by around three million people over the next 15 years and almost two in every five of these people will have or acquire a disability.²

At the same time, the number of informal carers per head of population is expected to decline sharply, as older carers pass away or become too infirm to look after their adult children. Amongst young families the capacity to provide care for a disabled child is declining, because for more and more families both parents need to work to pay the mortgage and meet other necessary expenses. (According to the National Centre for Social and Economic Modelling the number of principal carers for every 100 older persons needing informal care will fall from 57 in 2001 to 35 in 2031.³ Access Economics estimates that the replacement value of informal care, Australia-wide, is **\$30.5 billion** annually.⁴)

The projected increase in the proportion of the population with disabilities and declining informal support through unpaid carers will lead to very large increases in the costs of disability, which will add significantly to government outlays.

We need to plan ahead before the current unmet and under-met needs become overwhelming. The situation is similar to the problem identified in the 1980s, when it was recognised that an ageing population dependent on old age pensions would place an extreme burden on taxpayers. This led to the development of compulsory superannuation.

The current approach to supporting people with disabilities is also based on an outdated welfare model which is not efficient. It is focused on minimising costs in the short term rather than minimising costs and maximising opportunities over a lifetime. It is also poorly integrated with other support structures and the responsibilities of the Commonwealth and the states are unclear.

As a result, people with disabilities and their carers are not only amongst the most disadvantaged in Australia, they experience low rates of labour force participation and high rates of unemployment:

- In 2003 labour force participation rates for males and females with disabilities were 59.3% and 47.0% respectively, compared with 89.0% and 72.3% for males and females without disabilities, respectively, ranking Australia 13th out of 19 OECD countries.⁵
- The unemployment rate for people with disabilities seeking work was 8.6% in 2003 compared with 5.0% for people without disabilities. The 2006 Census suggests that the gap between the unemployment rate for people with disabilities and the national average had widened to more than twice the national average.⁶
- Disability Support Pension (DSP) recipients are amongst the poorest groups in Australia and in 2007 the recipients had spent an average of 8.7 years out of the past 10 years on the DSP ⁷.

Amongst families providing care and support to loved ones with non-compensable injuries the Australian Institute of Family Studies ⁸ estimates that:

- Sixty per cent of carers reported that they cared for a person with a disability for more than 100 hours per week.
- Thirty per cent of families with a carer receiving either Carer Payment or Carer Allowance had experienced difficulty in paying electricity, gas or telephone bills on time, compared with 14.6% for the general population.
- Almost twice as many carers were in poor physical health than the general population.
- Fifty one per cent of female carers and 31 per cent of males reported that they had been depressed for six months or more since they started caring.

Amongst carers who provide informal care full time and are in receipt of Carer Payment only 11% work part-time. Then, in more than 50% of cases when they are no longer eligible for Carer Payment, they shift across to other forms of government income support, because either long term disengagement from the workforce or the onset of physical disabilities or mental illness due to their caring roles have made them unfit for work.⁹ This is a huge cost to society.

In the Background Paper prepared for the Pension Review it was noted that people on Disability Support

Pensions are even poorer than single old age pensioners, because they face much higher costs. The Pension Review further noted that the best way to meet these costs is not through the income support system and in the final report, Dr Jeff Harmer, Secretary to the Department of Families, Housing, Community Services and Indigenous Affairs, noted that 'new approaches to funding services and support for people with disability is important to the long-term stability of the system. In particular, the idea of a National Disability Insurance Scheme is worthy of further consideration'.¹⁰

The costs of this scheme are currently being analysed by the Disability Investment Group, which was established by the Parliamentary Secretary for Disabilities, Bill Shorten, and which will report to Government shortly. At this stage the estimated costs are not publicly available but it is noteworthy that Brendan O'Reilly has said that the cost 'would be less than people think', while also calling for the scheme 'to be in place within 4 years'.¹¹

The timing of the introduction of an NDIS would need to balance the long term inter-generational effects of an ageing population against the likely shorter term effects of the Global Financial Crisis. Significantly, while adding to government expenditures, an NDIS would create major employment and business opportunities, as well as meeting the needs of people with disabilities, their families and carers. It would also reduce costs in the medium and long term by eliminating many of the inequities and inefficiencies in the current welfare-based system:

- First, by shifting to a needs based no-fault system the current major inequities between the few who have access to multi-million dollar payouts and the majority who receive very little support, and between the treatment of identical injuries depending on how they are acquired, would be eliminated.
- Second, in insurance models liability management is critical to cost containment and so every effort would be made to ensure that services are delivered as effectively as possible.
- Third, the opportunities for people with disabilities to work would be maximised, with an emphasis on education and training, as in workers' compensation schemes today. This would be facilitated through active case management to achieve as normal a life as possible and to minimise the risks of over-dependence on publicly funded support.
- Fourth, the insurance approach would create an automatic alignment between the interests of people with disabilities, families, carers, the community and

governments built on maximising opportunities and minimising costs over the life course. For example, a life-time approach to care would ensure that early intervention, therapy, equipment and home modifications are available as soon as they are needed following diagnosis or injury, leading to better and lower cost long-term outcomes.

- Fifth, families of people with disabilities would have confidence that the needs of their family member would be met, reducing unnecessary stress and risks of family breakdown, which are currently adding significantly to costs.
- Sixth, carers would be supported and sustained in their roles rather than burnt out and left exhausted, because informal care is both high quality and helps to contain long term costs, while carers would also be encouraged to work and so remain engaged in the labour force.
- Finally, properly structured an NDIS would lead to significant family and private investment in disability services, as is the case in education and health, ultimately reducing the costs to governments.

The theoretical underpinnings to an NDIS are also strong, as it is built on the models used for workers' and accident compensation, including most importantly the analyses by Meredith, Beveridge and Woodhouse.¹² Amongst economists, Kenneth Arrow, who later received the Nobel Prize for Economics, analysed individual and community welfare in the face of uncertainty proving that there is a net social gain from taking out insurance for medical costs and the costs of disability.¹³ In his work Arrow also included a category 'failure to recover', i.e. people with disabilities.

The practical underpinnings are also strong, as there are already no-fault insurance schemes to meet the needs of people injured in the workplace in NSW, Victoria, South Australia, Northern Territory and the Commonwealth and in car accidents in NSW, Victoria and Tasmania. There are also international examples of disability insurance schemes, such as the Accident Compensation Commission in New Zealand.

Addressing the National Press Club on 1 April 2009, the federal Parliamentary Secretary for Disabilities, Bill Shorten, described the NDIS proposal as 'a simple yet visionary and exciting idea... [that] would turn our current system of disability services on its head... [and remove] the last practical barrier to civil rights in this country'.¹⁴

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