



The Case for a National Disability Insurance Scheme



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Introduction



- Support for people with disabilities is delivered through a crisis driven welfare system with many falling through the gaps. Families provide care until they cannot continue or die.
- There is now bi-partisan agreement that governments have failed people with disabilities over many decades. Addressing the Press Club on 1 April, the Parliamentary Secretary for Disabilities, the Hon Bill Shorten, described disability as “the last frontier of practical civil rights in this country”



- Yet the theoretical and practical evidence for a fairer and more effective system is clearly demonstrated by existing social insurance schemes
- A **National Disability Insurance Scheme (NDIS)** would be equitable, more effective, provide planned support and maximise opportunities for people with disabilities, their families and carers over their life course; it is an idea that Shorten has described as “a simple yet visionary”
- A NDIS would also allow governments to anticipate the growing crisis amongst people with disabilities and carers due to demographic trends; it is time to plan ahead as we did with compulsory superannuation in the 1980s



- The next steps are a detailed feasibility study and to build ever stronger support across the disability sector, governments and the community

Overview



Key topics:

- Background and Recent Developments
- Why a NDIS?
- NDIS Key Design Features
- NDIS-Building Support and Next Steps
- Appendix A: A NDIS and Social Security Design Principles
- Appendix B: SHUT OUT



Background and Recent Developments



The idea of disability insurance is built on workers' and accident compensation: Meredith (1910), Beveridge (1942), Woodhouse (1967 and 1974). These schemes work well in Australia as does the ACC in NZ. In economics, Kenneth Arrow (1963): *Uncertainty and the Welfare Economics of Medical Care*, which included insurance for "failure to recover"



Disability insurance is also supported by the work of John Rawls in *A Theory of Justice* (1971) and his concept of a "veil of ignorance". More recently, Gunter Schmid (2003) and Brian Howe (2007) have promoted the ideas of risks over the life course and insurance. John Walsh, et al (2005): *Long Term Care Actuarial Analysis on Long Term Care for the Catastrophically Injured* and interest from Insurance Ministers and officials.



The 2020 Summit in April 2008 recommended:

"Establish a National Disability Insurance Scheme, similar to a superannuation scheme, to support the families of children with brain injury from birth and other non-insurable injuries." (Recommendation 6.6)

Background and Recent Developments



In November 2008 Community and Disability Service Ministers established a Life Long Care Working Group and agreed to it moving towards nationally consistent catastrophic injury schemes

The Commonwealth Government in 2008 signed the UN Convention on the Rights of Persons with Disabilities and in July agreed to accede to the Optional Protocol which establishes a complaints mechanism for breaches of the treaty



National Disability Agreement replaced the CSTDA and provides for increase in Commonwealth Government disability funding of 3% (real) over next 5 years, together with some State funding increases

“Who cares...?” Report by the House of Representatives Standing Committee on Family, Community, Housing and Youth, April 2009

The most significant increases in the DSP, Carer Payment and Carer Allowance for more than 30 years in the 2009/10 Budget



The Pension Review by Dr Jeff Harmer, which was released with the Budget, noted that “new approaches to funding services and support for people with disability is important to the long-term sustainability of the system. In particular, the idea of a National Disability Insurance Scheme is worthy of further consideration” (Finding 23)

Background and Recent Developments



National Disability and Carer Alliance formed. Members are the Australian Federation of Disability Organisations (AFDO), Carers Australia and National Disability Services (NDS); first priority is the introduction of an NDIS

ACTU Congress and The Australian have supported a NDIS

Labor Party Conference on 1 August recognised “...the call for an examination of the merits and feasibility of an insurance model to meet the costs of long-term care for people with disabilities. Such a model would provide a national scheme of individualised life-time care and support for people with disabilities from the point of diagnosis, providing certainty and a whole-of-life perspective people with disabilities and their carers”

SHUT OUT, National Disability Strategy Consultation Report

Disability Investment Group, which was established in April 2008, has been working on the details of a NDIS and will report to government shortly



A NDIS is a visionary and transformational reform which would rank along side Medicare and compulsory superannuation as a legacy reform. It would transform the lives of people with disabilities, families and many carers, especially very long term carers

Why a NDIS?



Equity

Highly inequitable differences in treatment of people with similar levels of disability or injury, because compensation in most cases is based on proving fault or cause

Inequitable differences in service standards between States, regions and local government areas which is also a barrier to employment mobility of people with disabilities and their families

Eligibility for a NDIS would be based on needs and so would be fair



Sustainability

Rates of disability are rising (IVF, older mothers, increasing community violence and people with disabilities living longer)

Reductions in the community's capacities to provide informal care, due to carers ageing eg NATSEM estimates that the number of carers per 100 older persons will decline from 57 in 2001 to 35 in 2031; and changing household structures

An AIFS survey suggests carers are already experiencing high rates of financial stress, poor mental and physical health and in 60% of cases >100 hours per week of care is provided



Short term rather than investment approach, eg carers are "burnt out" rather than nurtured and supported and too little early intervention

Little research into best practice even though governments are spending billions
A NDIS would meet unmet needs, provide intergenerational neutrality and create efficiencies/continuous improvements in care and support

Why a NDIS?



Standard of Living

Many people with disabilities are living in poverty (on average the Pension Review found they were poorer than single old age pensioners), in part because their costs of living are higher than for others on income support

A NDIS, through its planned entitlements to care and support, would address this problem, which cannot be addressed efficiently through the income support system, through a person/family centred approach



Participation and Opportunity

Labour force participation rates for people with disabilities are two-thirds the national average and the unemployment rate is more than twice as high

Very few people come off the DSP (less than 3% per annum cease receiving income support) and most long term carers become disengaged from the labour force (more than 50% of those who cease receiving Carer Payment go onto to another form of Government income support)

A NDIS would take a lifetime approach, recognising the changing needs of people with disabilities and their carers, rather than providing care at a single point in time, leading to better long term social and economic outcomes.



A NDIS would also seek to minimise the costs of care and maximise opportunities over a person's lifetime and so would create an automatic alignment between the needs of people with disabilities and the management of the Scheme.

NDIS Key Design Features



Eligibility

People with permanent disabilities acquired before age 65 would be eligible for life, without reference to cause and treated equally based on needs

No fault; the provision of support and care for people with disabilities would be separated from legal action for negligence/culpable behaviour

Principal beneficiaries would be those with profound and severe disabilities (approx 700,000) who need assistance with daily living tasks (self care, communication and mobility) and so well suited to a universal insurance 'solution'



Benefits

Principal Benefits: care, support, therapy, access based on needs assessment (not income support, as this is provided by the DSP)

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 market place for services to drive efficiency and innovation



NDIS Key Design Features



Role of Families/Carers

Families expected to fulfill normal age-appropriate caring roles

Tailored support for carers, through respite, information, counseling, 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

Restricted payments to family members as carers to reduce risk of fraud



Governance and Scheme Management

Pooling of individual risks through the schemes

Potential mix of State and Commonwealth schemes with Commonwealth coordination to ensure a consistent national framework:

- Levies funded on a consistent basis across States and Territories
- National standards of 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 and independent review/appeals process

Research/Best Practice

Research into best practice and prevention strategies to drive effectiveness, efficiency and reduce long term costs (like TAC)

NDIS Key Design Features



Funding Arrangements

Workers compensation schemes in all States (no change in funding and to remain no-fault)

Motor vehicle accident schemes (change in third-party motor vehicle insurance to shift to no fault in Qld, SA and WA; no change in other States and Territories)

Medical indemnity (no change in funding but to become no fault; separation of compensation from legal actions for negligence or culpable actions)

Extension of State compensation schemes to cover other catastrophic injuries, also on a no-fault basis

Shift away from reliance on lump sum payouts which are inefficient because there is no pooling of risks and in 75% of cases recipients become reliant on government funded support within 20 years

Fully funded or at least partially funded NDIS with funding through a Medicare-type levy/general revenue because disability can affect anyone but will not affect everyone, so community charge based on community rating principle and capacity to pay most appropriate

Significant offsets for government due to better employment outcomes and lower medical, hospital, homelessness and judicial costs

Opportunities for families to make additional private investments, offsetting some of the additional costs to governments of a NDIS

Potential additional private insurance, as now, through TPD and income protection



NDIS-Building Support

Visit www.ndis.org.au Making a NDIS a reality is everyone's responsibility, so sign up your organisation and ask your clients and staff to take one or more of these actions:



NDIS-Next Steps



1. A NDIS is the light on the hill
2. The theoretical and practical underpinnings for a NDIS are very strong. It would transform the opportunities for people with disabilities, their families and carers, creating person-centred more efficient solutions
3. Governments, people with disabilities, families, carers and disability service providers are increasingly coming together behind this idea
4. It is time to look forward as Australia did in the 1980s with the introduction of compulsory superannuation and introduce a NDIS as the centre-piece of a new National Disability Strategy, before the current crises worsen
5. **The next steps are:**
 1. To continue to build stronger disability sector, government and community support for a NDIS nationally and in each State
 2. To persuade the Commonwealth Government to establish a **Feasibility Study** into a NDIS and engage with the States



Appendix A: A NDIS and Social Security System Design Principles



Pension Review Background Paper outlines 5 key principles:

1. Basic acceptable standard of living
2. Equitable
3. Targets payments based on financial needs using income and assets tests
4. Promotes participation and self-provision
5. Sustainable with broad community support, affordable over the cycle and in long term with an ageing population



Basic Acceptable Standard of Living



Current income support

Major income support is DSP (Carer Payment and Allowance for carers), which was increased significantly in the 2009/10 Budget, following the Pension Review

DSP recipients are amongst the poorest in the community and on a range of measures are even poorer than single old-age pensioners due to higher costs. The costs of disability are better addressed through the service system and therefore were out of scope of the Pension Review



Current services

Provided primarily through the NDA (previously CSTDA) and HACC, based on “demand management”

AIHW estimates, conservatively, that there were 23,800 people with unmet accommodation needs and 9,400 people with community access needs in 2005



Other critical shortages include early intervention therapy, aids and equipment and respite services

NDIS services

Funding for an adequate level of service for people with disabilities based on needs and designed to maximise the potential of individuals and minimise support costs over their lifetime

Equity



Current system

Huge differences in treatment of people with similar levels of disability or injury

Compensation based on proving fault or cause

For those with non-compensable injuries, the provision of NDA services is not equitable; it is crisis driven, requires families to describe their situations in the most abject terms, causes great stress and management of the needs registers plays a big role



Quality and timing of services based on disability, injury and luck

“Managing demand” contributes to family stress and wastes scarce resources

Inequitable differences in service standards between States, regions and local government areas which is also a barrier to employment mobility of people with disabilities and their families

NDIS



Services based on need (rather than cause or type of disability) and provided on a timely basis to maximise long term outcomes

National standards that would treat people with similar disabilities equally and enable people to move without losing services

Promotes Participation and Self-Provision



Current situation

In 2003 labour force participation rates for males and females with disabilities were 59.3% and 47.0%, compared with 89.0% and 72.3% for males and females without disabilities, ranking Australia 13th out of 19 OECD countries

Unemployment rate for people with disabilities was 8.6% in 2003 compared with 5.0% for people without disabilities. The 2006 Census suggests that the unemployment gap had widened to more than twice the national average

DSP recipients in 2007 had spent an average of 8.7 years out of the past 10 years on the DSP and less than 3% come off the DSP per annum

Transport is a major barrier to inclusion in education, work and the community

Long waiting lists for the most basic services reduce dignity and self esteem and hence capacity for participation and self provision

Amongst carers 18,000 stopped receiving carer payment in 2007/08 but 53% went on to other forms of government income support

NDIS

Early intervention and other services to maximise long term independence and potential and promote dignity and self esteem

Training/development/employment/return to work strategies/transport assistance are integral to liability management and quality of life; a NDIS would extend this approach from work place injuries to all disabilities

A NDIS would promote part-time employment for carers and connection to the labour market



Sustainability

Carers



Families often experience poverty and depression and continue to care until they die, collapse or relinquish their child

There are many carers aged in their 80s and 90s hoping their disabled child will pre-decease them. For younger families they must choose between the two incomes they were planning and caring roles

AIFS survey suggests carers experience high rates of financial stress, poor mental and physical health and in 60% of cases >100 hours per week of care is provided



In contrast a NDIS would:

- Provide the difference in care and support between normal chronological needs and actual needs based on functional assessments
- Nurture and support families to provide informal care to loved ones through respite, counseling and other services for as long as possible
- Facilitate opportunities for carers to combine caring with employment and a normal life
- Plan for changes in care reflecting changing needs and capacity including transition to formal care based on family needs
- Align individual, family, carer and scheme interests through the management of liabilities over the life course



Sustainability



Growing unfunded liability

CSTDA and HACC services are miserably rationed through long waiting lists

Rate of incidence of disability at birth is rising, while people with disabilities are living longer

Carers are ageing eg NATSEM estimates that the number of carers per 100 older persons will decline from 57 in 2001 to 35 in 2031; and changing household structures are reducing the propensity to care

There is a rapidly growing unfunded liability as demand for disability services is rising in real terms at 5-7% pa



The risks of disability and/or the need to become a carer are risks we all face; therefore these are issues for all Australians, not just those currently needing more support

In contrast a NDIS would:

- Provide entitlements based on needs; not a welfare/charity system
- Recognise and provide for current future liabilities by setting premiums based on experience and future needs
- Be consistent with the Australian sense of a fair go. The community would be supportive of more services for people with disabilities and carers and be prepared to contribute to its costs if it better understood the current inadequate and inequitable situation



Sustainability



Data

Lack of quality data on disability incidence, needs or mapping to current and future services

Research

Disability services cost \$6 billion each year, while there is little research on causes of disabilities or best practice support and care models

Sustainability

Even the largest and most efficient disability organisations are underfunded and so are eating into their capital reserves. For many smaller disability organisations their committees of management are exhausted, yet fears of loss of control are preventing restructuring

Prevention

Lack of prevention strategies e.g. role of alcohol in violent injuries and abnormal development, compared with TAC advertising which has now reduced Victoria's death toll per car to the lowest in the world



Accessibility

Failure of voluntary building code to provide universal accessibility or adaptability despite need to provide for ageing in place

Appendix B:

SHUT OUT-Main Findings



- 750 submissions and 2,500 attended the public consultations
- Lack of social inclusion, social isolation and multiple barriers to meaningful participation in the community
- The disability service system is broken and broke, chronically under-funded and under-resourced, crisis driven and struggling against a vast tide of an unmet need; it often is a barrier to, rather than a facilitator of, participation
- Need for a lifetime care and support scheme
- Too few people with disabilities are able to access meaningful employment
- Lack of access to buildings and facilities is a barrier to full participation in the community
- The education system has little capacity to meet the needs of students with disabilities, is chronically under-funded and staffed by teachers who receive little or no training with regard to disability

SHUT OUT-Conclusions and Government Response



The National Disability Strategy should address four strategic priorities:

- Increasing the social, economic and cultural participation of people with disabilities and that families, friends and carers
- Introducing measures that address discrimination and human rights violations
- Improving disability support services
- Building in major reform to ensure the adequate financing of disability support over time



In response to SHUT OUT Minister Macklin stated:

“The Government is determined to turn around the years of neglect to make sure people with disability have the opportunity to be involved in their communities, where possible have a job and a life that is meaningful and worthwhile.”

