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The Case for a National Disability Insurance Scheme



Inquiry into Better Support for Carers
Ms Annette Ellis MP, Chair, House Standing Committee on
Family, Community, Housing and Youth



Bruce Bonyhady, Chairman, Yooralla
15 December, 2008



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Overview



- 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. They do so because there is no alternative or because they feel it is their duty and responsibility despite huge costs to their health and well being
- **This is a national disgrace**
- Yet the theoretical and practical evidence for a fairer and more effective system is clearly demonstrated by existing social insurance schemes
- The crisis amongst people with disabilities and carers will grow due to demographic trends; it is time to plan ahead as we did with compulsory superannuation in the 1980s
- **A National Disability Insurance Scheme** would provide planned support for people with disabilities and their carers over their life course and maximise rather than minimise the opportunities for people with disabilities and their carers. It should be a key recommendation from the **Inquiry into Better Support for Carers**



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Overview



Key topics:

- Background
- Social Security Design Principles
- NDIS Design Features
- NDIS Funding
- Conclusions





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Background



The idea of disability insurance is built on workers' and accident compensation: Meredith (1910), Beveridge (1942), Woodhouse (1967 and 1974)

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 transitional labour markets and risks over the life course, including social insurance models

John Walsh, et al (2005): *Long Term Care Actuarial Analysis on Long Term Care for the Catastrophically Injured*

Recommendation to the 2020 Summit:



"The time is right to reform the disability sector: to shift from the current crisis-driven welfare system to a planned and fully-funded **National Disability Insurance Scheme** that will underwrite sustained, significant long-term improvements in meeting the needs of people with disabilities and their families."



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Background



Final Summit Report (Recommendation 6.6):

“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.”

There are a number of examples of disability insurances schemes which are working very efficiently in Australia, e.g. TAC and WorkCover in Victoria (and internationally, e.g. ACC(NZ))



A National Disability Insurance Scheme will require close cooperation between the Commonwealth and States; at this stage they have established a Life Long Care Working Group to examine a catastrophic injury scheme

A National Disability Insurance Scheme has strong theoretical underpinnings and today's schemes are working very well



A NDIS is a visionary and transformational reform which would rank along side Medicare and compulsory superannuation as major social and economic reforms. It would transform the lives of many carers, especially very long term carers



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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





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Basic Acceptable Standard of Living



Current income support

Major income support is DSP (Carer Payment and Allowance for carers)

DSP recipients are amongst the poorest in the community and on a range of measures are even poorer than single old-age pensioners

Future income support

Under review by the Pension Review Task Force

Current services

Provided primarily through the 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





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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 CSTDA 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



NDIS

Treats people with similar disabilities equally

Services based on need and provided on a timely basis to maximise long term outcomes





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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% respectively, compared with 89.0% and 72.3% for males and females without disabilities, respectively

Unemployment rate for people with disabilities was 8.6% in 2003 compared with 5.0% for people without disabilities

DSP recipients in 2007 had spent an average of 8.7 years out of the past 10 years on the DSP

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

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; NDIS would extend this approach from work place injuries to all disabilities





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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 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 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





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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 growing 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 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





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Sustainability



Data

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

Research

Lack of funding for research on causes of disabilities or best practice support and care models, despite high community costs



Sustainability

Disability organisations are under-funded and so are eating into their capital reserves, while for many smaller disability organisations their committees of management are exhausted

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



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NDIS Key Design Features



Eligibility

People with permanent disabilities, especially severe and profound disabilities, under age 65, without reference to cause, treated equally based on needs and dovetailed with aged care system

No fault; separate resource provision for people with disabilities from legal action for negligence/culpable behaviour



Benefits

Principal Benefits: care, support, therapy, access (not income support)
Services based on functional impairment and centred around individual needs and choices

Case management to facilitate independence, maximise potential and plan transitions over the life course

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

Scope to empower individuals to choose from approved services to improve well being e.g. TAC





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NDIS Key Design Features

Role of Families/Carers

Families expected to fulfill normal age-appropriate caring roles

Families able to choose to work or provide informal care, as for families without disabled members

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

Governance and Scheme Management

Pooling of individual risks through the schemes

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
- Common standards of care, support and case management

Governance framework to manage scheme assets, liabilities and data collections to optimise scheme performance and monitor usage

Independent review/appeals process

Other Features

Research and prevention strategies to reduce long term costs (like TAC)





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NDIS Funding Arrangements

Current situation

Workers compensation schemes in all States (no fault)

Motor vehicle accident schemes (no fault in NSW, Vic, NT, Tas only)

Medical indemnity (fault based)

Litigation is expensive as fault and contributory negligence are difficult to prove and damages are difficult to quantify.

Lump sum pay outs for compensable injuries (but in NSW study in 95% of cases lump sum recipients were on social security within 20 years)

Very limited demand for TPD insurance ("it won't happen to me") and insufficient to cover life time care

CSTDA funded from general revenues

NDIS

Workers compensation, motor vehicle accident and medical indemnity all no fault (separation of compensation from legal actions for negligence or culpable actions)

Funding through a Medicare-type levy/general revenue because disability is a risk we all face and so community charge most appropriate

Fully funded or at least partially funded scheme





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Conclusions



1. A NDIS would transform the opportunities for people with disabilities, their families and carers, as the scheme would automatically align their interests and the community's and provide the necessary funds. It is a light on the hill
2. The social and economic theory underpinnings for a NDIS are very strong
3. The current inadequate and inequitable support for many people with a disability and their carers is a national disgrace. Moreover, the failings under the current welfare approach will grow in the years ahead due to demographic trends that are already underway
4. It is time to look forward as we did in the 1980s with the introduction of compulsory superannuation
5. There is an opportunity for the **Inquiry into Better Support for Carers** to build on the momentum created by the 2020 Summit and contribute to Australia leading the world through a National Disability Insurance Scheme
6. A National Disability Insurance Scheme should be a key recommendation from the Inquiry into Better Support for Carers

For more details: www.natdis.com.au