

**‘Australia’s National Disability Insurance Scheme:
Its Design, Progress, Campaign Lessons, Challenges and
Opportunities’**

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Introduction

Ladies and gentlemen, thank you for inviting me to speak about Australia’s National Disability Insurance Scheme or NDIS.

It is an honour and a privilege to be invited to North America – the crucible of so many pioneering public policies and ideas... including universal medical and health insurance.

The great American political philosopher John Rawls believed that when we develop new social contracts all parties should imagine themselves as being behind a ‘veil of ignorance’.

Behind this veil, Rawls argued, ‘you know nothing of yourself and your natural abilities, or your position in society’.

His view was that ignorance of personal position was essential – so that the choices we make are based upon moral considerations, rather than self- or class-interest.

This belief led Rawls to develop three guiding principles:

1. Each one of us has the same indefensible claim to equal basic liberties;
2. Each one of us should have equality of opportunity, regardless of our background; and
3. Social institutions should be arranged so that any inequalities of wealth or income work to the advantage of the most disadvantaged members of a community.

Rawls called this last point the ‘difference principle’.

In Australia, until the NDIS was introduced our social institutions failed to meet Rawls's 'difference principle'.

In 2010, the OECD found that 45 per cent of Australians with a disability were living at or below the poverty line, the worst outcome of any OECD country.

Australia's record in terms of employment of people with disability was – and remains – poor, ranking in the bottom one-third of OECD countries.

And, most disturbingly, people with disability are significantly overrepresented in Australia's jails.

In short, until the NDIS, Australians with disability were born into a world where they were treated as second-class citizens.

One of the lessons of the Australian experience is that the costs of even a second-class disability system are prohibitive.

Since the 1990s, disability expenditure by Australian governments has been increasing at between 7 and 8 per cent in real terms each year.

There are demographic reasons for this surge in demand:

- major advances in the life expectancy of people with a disability – combined with the ageing of the parents caring for them – meaning increasing numbers of carers are pre-deceasing or forced to relinquish a family member with a disability,
- families are having less children – reducing the number of siblings able to care for a brother or sister with a disability,
- rates of marital breakdown are increasing, especially amongst families with disabled children, and
- the participation rate of women in the workforce is increasing – further reducing the availability of family carers.

Increasing life expectancies for people with disability...Ageing carers ...
Smaller families ... An adult population that has less and less time for
family care: ...

... these demographic fronts created a perfect storm for disability services
– with governments forced to focus more on the short-term issues of cost
and emergency care and less on the long-term need to increase
opportunity and reduce disadvantage.

As a consequence, until the NDIS, the disadvantages faced by Australians
with a disability – and their families and carers – were becoming more
entrenched ... and their chances of claiming full citizenship more remote.

Little wonder that a 2011 report by Australia's pre-eminent economic
think tank, the Productivity Commission, found that the nation's
disability system was:

‘Underfunded, unfair, fragmented, inefficient and gives people
with a disability little choice.’

In other words, Australia's public welfare model for disability services
was broken.

Further, Australians could only insure privately against the risk of being
born with or acquiring a significant and permanent disability in cases of
workplace accidents, proven medical negligence and some injuries from
motor vehicle accidents.

In short, Australia's private and public sectors had failed to either insure
or provide for significant and permanent disability.

This is despite the fact that:

- the risks of permanent disability before the onset of old age at a
population level are low and known,
- the impact in each individual case is high,

- and the risks of permanent disability are insurable – so long as the risk pool from which insurance premiums are collected is sufficiently large.

And that is why Australia is implementing the NDIS.

Insurance, Not Welfare

The NDIS was established on 1 July 2013.

Currently, the Scheme is being piloted in seven trial sites and has 19,817 participants, with another two sites due to commence shortly.

When it is fully operational, in 2020, the Scheme will include 460,000 participants out of a total Australian population of around 24 million people – and government expenditure on disability services will have doubled from 0.5 per cent of GDP to 1 per cent.

The Scheme is being funded through an increase in the surcharge that Australians pay for medical and health insurance, the Medicare levy, and general revenues.

As a consequence, the funding model reflects an individual's capacity to pay. This approach is consistent with Rawls' philosophy.

What all taxpayers receive in return is:

- security,
- peace of mind, and
- certainty of support on the other side of Rawls' veil of ignorance, where none of us know whether we will become disabled ourselves or have a child or grandchild with a disability.

With the NDIS in place, every Australian who is born with or acquires a disability before the age of 65 and whose disability is permanent and which significantly affects their functional capacity will be covered.

The age cut off reflects the fact that the NDIS is an insurance scheme.

After all, the disabilities most of us will acquire as we grow old are almost inevitable – and therefore not insurable risks.

You can save to cover these costs and assist with caring, but you cannot insure against them.

The NDIS includes people with intellectual, physical, sensory and psychosocial disabilities.

It is based on need and uses a functional assessment approach.

It also includes early intervention services for children and adults with progressive disabling conditions.

The Scheme is revolutionary.

It is revolutionary ...

not because it is replacing the old system,

not because it is doubling funding,

not because it has created a new Federal body – the National Disability Insurance Agency, of which I am Chairman.

The NDIS is revolutionary because it is taking an entirely new approach to disability services ...

an approach that is built around the needs and the potential of the individual,

an approach that sees the individual as a life-long investment, rather than a year-to-year unit of cost, and

an approach that replaces the welfare model of disability services with an insurance model.

In short, the NDIS is based on insurance principles.

Let me spell out those principles for you.

Traditionally, the costs of disability services are approached using a short- to medium-term outlook.

Governments plan for expenditures over a 12-month period to at most a five-year time frame – and the funds available change depending on the economy, tax revenues and the requirements of other portfolios.

Consequently, disability services must perennially justify their existence – and there are always short- to medium-term pressures to cap costs.

The insurance model is very different.

Under an insurance model, expenditure is factored in over the life of an individual and scheme sustainability is measured by calculating the total future costs of all those who are insured.

This approach creates an incentive to make short term investments that reduce long-term costs.

For instance, the best way to reduce long-term costs is to increase an individual's independence and lift his or her participation in community and work.

That might mean ...

giving a child a wheelchair that's fit for purpose when it is needed,

or providing early intervention so that a young person with an intellectual disability can learn the skills they need to live and work in the community,

or having an aide come around to help a person with a physical impairment get out the door to university or work or the community.

All of these examples and many more highlight that the best way to overcome the inequalities that people with a disability face every day is to maximise independence and social and economic participation.

This approach has the added benefit of reducing the long-term consumption of services, and provides an additional benefit to the broader economy – boosting Gross Domestic Product.

Let me spell out some of those economic benefits.

The cost of the NDIS, once it's fully operational, will be \$22 billion a year.

By comparison a 2012 study by PricewaterhouseCoopers found that – unless the NDIS was implemented – government spending on disability would increase to between two and three times the projected cost of the NDIS. The NDIS therefore makes disability spending fiscally sustainable in the long term.

Not only that, the Productivity Commission found that the NDIS would result in an additional 320,000 people with a disability and 80,000 carers being employed by 2050 and boost GDP by 1 per cent.

Local and Individual

Although the NDIS is an Australia-wide reform, it is more portable than national.

Currently, disability services in Australia are state-based.

That means the types and standards of services differ from state to state.

The Productivity Commission referred to this service coverage as a 'postcode lottery'.

It is another indicator that Australia was failing to meet Rawls' principles of equality.

It has also meant that a person with a disability found it difficult to move from one state to another – because they may not be able to receive the same standard of support.

The NDIS will put an end to that injustice. This is reflected in a major structural shift in financial responsibility for disability from the States to the Commonwealth Government, because in Australia, as is the case in most countries, it is only the Commonwealth which has the broad and deep revenues sources capable of underwriting a long-term insurance scheme like the NDIS.

The NDIS also embraces consumer-directed payments and individualised support models that have emerged in a number of countries, including Canada.

If a person with a disability wants to move to another state their entitlement to the NDIS – and therefore their level and standard of support – will move with them.

Each participant will receive the funding necessary to provide 'reasonable and necessary' supports.

They will have 'control and choice' over the funds they receive.

And they will be able to tailor their supports to their needs.

We expect that this individualised model will drive innovation, and that the new markets for disability supports will embrace wider access to mainstream services, as well as new specialist services.

Over time, the market will lead to increased efficiency and effectiveness.

With that in mind, we are developing an outcomes framework which balances individual, family and government contributions and uses the market to allocate resources most efficiently.

Local area coordination is an essential part of the Scheme.

It's essential because we want to encourage the development of highly decentralised services, build local mainstream responses, promote inclusion, build social capital and ensure that as many decisions as possible that affect local people are made locally.

Subsidiarity is therefore another key principle on which the NDIS is based – as is the need to harness technology to shift power to people with disability rather than create a digital divide.

That is why we want to create an e-market that will help participants to become informed consumers and are working with leading global technology companies such as Apple, Microsoft and Google to use digital disruption to make services more accessible.

Challenges and Opportunities

The rollout of the NDIS is currently on time and on budget – with a satisfaction rating of more than 90 per cent from participants.

While these results are encouraging, there are simultaneously challenges and enormous untapped potential ahead.

One challenge is to ensure that education, health and other mainstream services fulfil their universal service obligations to people with disability, as part of a broader National Disability Strategy.

Another is developing the Scheme in culturally competent ways, so it meets the needs of Australia's Aboriginal and Torres Strait Islands people and other culturally and linguistically diverse groups.

One of the current trial sites is in the Barkly Shire area of the Northern Territory, which is one of the remotest parts of Australia with an area the

size of Poland and just 8,000 inhabitants.

There we are taking a community development and capacity building approach, slowly building trust, looking to use technology to overcome some of the tyranny of distance and believe that the NDIS must be tailored to build on the strengths of these communities as well as the individual participants.

One of the benefits of the NDIS that is yet to be fully realised is that since the inception of the Scheme two years ago, we have been aggregating data from participants.

Right now, we have data from less than 20,000 participants.

By 2020, we will have data from 460,000 participants.

The data includes an outcomes framework for people with disability which measures choice and control, independent living, relationships, health and well-being, home, lifelong learning, work and social, community and civic participation, which will enable us to measure progress individually, for particular groups or locations or service providers and over time.

The more data we aggregate and analyse the better the NDIS will become.

That's because we are building an evidence base which will allow the Scheme to continue to learn and build beyond the trial phase, as part of what insurers call the prudential insurance governance cycle.

This cycle will lead to continuous improvements – making the NDIS more refined, more sustainable and more beneficial to its participants with every passing year.

For that to occur we need to be prepared to, as the statistician Nate Silver says, 'stop and smell the data' ... and continually analyse the costs and benefits of the Scheme.

After all, Big Data doesn't just tell us about what happened yesterday. It can also tell us what is probably going to happen tomorrow.

Ultimately, the analysis of data and the policy and practice actions that will flow from that analysis will provide information useful to communities and policy makers around the world.

The data will help us to understand in detail more about our society and disability, about the lifetime costs of preventable causes of disability such as diabetes and foetal alcohol syndrome and how different types of support can lead to better outcomes for people with disability.

In time, I expect the NDIS will make Australia more physically accessible, because we will be able to measure the real costs of an inaccessible society through detailed actuarial analysis.

I am certain that the analysis will also unearth surprises, because we are in the infancy of data aggregation and analysis, and so cannot know what hidden connections we will find.

But what we do know is: Australia is set to aggregate and analyse the biggest data set on disability in the world, within a long-term insurance framework.

As a consequence,

- we will learn,
- we will improve,
- we will make a difference to the lives of many people, and
- I expect we will have an increasing impact beyond Australia and so make the NDIS more portable than national.

Campaign Lessons

I know that one impact the NDIS has already had is being felt here in Canada – where there is a campaign underway, Every Canadian Counts, to establish a similar insurance scheme.

With that in mind, I'd like to quickly detail some of the lessons from the Every Australian Counts campaign.

The idea of a National Disability Insurance Scheme is not new, having been highlighted and theoretically proven by Professor Kenneth Arrow in the 1960s.

Australia first considered adopting a social insurance system to support Australians with a disability in the 1970s.

But without bipartisan support in Australia, that forerunner to the NDIS died with the dismissal of the Whitlam Government in 1975.

By 2008, the disability movement had learned the lessons of 1975.

And that lesson was this:

For an NDIS to be accepted it had to be bipartisan – and the disability sector had to be united.

Not only that, the case for change had to be supported by hard economic data because – in Australia – all public policies must run the gauntlet of Treasuries and Finance Departments.

In other words, to achieve change we had to create a movement and build a case.

Between 2008 and 2011, both of those steps were taken.

First, *Shut Out*, a report documenting the lives of hundreds of Australians living with a disability, was commissioned and published.

Then, three peak bodies representing people with a disability, carers and service providers united to form a new body, the National Disability and Carers Alliance – which was a world-first.

Meanwhile, the Productivity Commission was given the task of investigating the bona fides of an NDIS.

The Productivity Commission concluded that the economic benefits of the NDIS would far outweigh its costs.

Ultimately, though, what made the NDIS a reality was unity.

The NDIS was the catalyst for the disability sector not just to unite, but to speak with one voice.

Together, we created and were united in our support for the Every Australian Counts campaign.

The campaign raised awareness about the lives of some of Australia's most vulnerable citizens – and spoke about the need to make a difference to the lives of people with a disability and carers and families.

That unity of purpose helped turn a previously balkanised disability 'sector' into a united disability 'movement'.

The campaign featured people with disability, their families and carers, telling their stories with great courage and authenticity.

And it used technology brilliantly to mobilise a grassroots movement of more than 150,000 people.

Together, they took the NDIS from a peripheral to a mainstream issue – making the establishment of the NDIS an almost inevitable outcome.

Conclusion

The NDIS is therefore a testament to the power of citizens to change society for the better.

It is an example of governments doing what people cannot do for themselves.

In Australia, the Scheme is the legacy social and economic reform of our generation.

There is still a mountain to climb over the next few years as the NDIS is fully rolled out across Australia.

But I am confident we will climb our Mt Everest.

What gives me heart is the hard work and dedication of the many people who have added their voices, energy and commitment to the NDIS.

In the National Disability Insurance Agency, 18 per cent of our staff have a disability and more than 50 per cent have a lived experience of a disability.

For the staff of the Agency, the NDIS is not just a job. It is a mission.

It is an opportunity to transform Australia.

And, so, slowly and surely – one participant at a time – the NDIS is making Rawls's theory of justice as fairness a reality for Australians with a disability.

And at long last, people with disability in Australia have the opportunity to claim the full citizenship that, until now, has been inaccessible.

Thank you.