**‘Creating the Perfect (Disability) Storm through Inclusive Collective Leadership’**

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I am delighted to be able to contribute to this important discussion on how collective and inclusive leadership led to the creation and initial design of Australia’s National Disability Insurance Scheme or NDIS and to provide some context to this reform.

I have entitled this presentation: Creating the Perfect (Disability) Storm through Inclusive Collective Leadership, because it was this collective and inclusive leadership, in which the whole was so much more than the sum of the parts, which led to the NDIS.

May I therefore especially acknowledge my fellow panel members and fellow leaders, Eddie, John and Kirsten with whom I have worked very closely on designing, campaigning for and operationalising the NDIS. I would also like to acknowledge Sam, with whom I am now collaborating in his role as General Manager Strategic Advice, Research and Inclusion Division at the National Disability Insurance Agency.

The NDIS at 30 June of this year after seven years of operation is now directly supporting nearly 400,000 Australians with disability. It is available in all parts of Australia and when it is fully operational, it will support around 500,000 participants, out of a total Australian population of around 25 million people or around 2 per cent of the population. Amongst the current participants more than 175,000 are receiving support for the first time. Most of the next 100,000 expected participants will also be people being supported for the first time, implying that more than one half of total participants will be receiving disability supports for the first time in their lives, as a result of the NDIS.

There are also nearly 15,000 active service providers, more than three and a half times the number of service providers four years ago.

The Scheme’s clients includes all those Australians who are born with or acquire a disability before the age of 65 and whose disability is permanent and which significantly affects their functional capacity.

The NDIS includes people with cognitive, physical, sensory and psychosocial disabilities, as well as early intervention services, especially for children and eligibility is based on a functional assessment, rather than a medical diagnostic approach.

All participants receive ‘reasonable and necessary’ benefits based on their individual needs, which reflect their goals, the sustainability of their informal supports and functional impairments. The benefits encompass support for activities of daily living, access to the community, therapy services, essential assistive technology and capacity building consistent with the insurance approach.

The NDIS does not include income support for people with disability who cannot work, as this is provided under separate arrangements in Australia.

The total cost of the NDIS, once fully operational, will be $22 billion a year and it means there will be a doubling of expenditure by Australian governments on disability supports and services from 0.5 per cent to 1 per cent of GDP between 2013 and 2021. This is a very large shift in national resources and over this period the NDIS will also account for about 20 per cent of the new jobs created in Australia.

But this growth in government spending on disability is not the key aspect of the NDIS which is transformational.

What truly makes the NDIS revolutionary is the unique way it brings together four key organising and operating principles.

First, the NDIS is an insurance scheme. As an insurance scheme it seeks to minimise lifetime costs and maximise lifetime opportunities. This contrasts with traditional welfare models of support which do not invest in people with disability and seek to minimise budgetary costs in the short term and not the long term.

As an insurance scheme, the NDIS also continually compares forecasts with experience and invests in research to learn and improve long term outcomes for people with disability, their families and carers.

Second, the NDIS is controlled by the individual with a disability and their family. They have the power. They are free to choose.

The Scheme therefore embraces the shift to consumer-directed and personalised supports that have emerged in a number of countries, but we are implementing this market-based approach on an unprecedented scale.

Markets are being harnessed to serve people with disability and over time we expect that ‘control and choice’ will unleash new and powerful market forces which will lead to much greater efficiency, effectiveness and innovation.

Third, the NDIS recognises that governments alone cannot and should not be responsible for all care, because a quality life and citizenship are based on loving relationships, friendships and sufficient government funding for an ordinary life.

The NDIS will be making a major investment in family and community capacity and inclusion, through an approach called Local Area Coordination—an approach which already has a long track-record of successfully developing local service responses in Australia and which has been adopted internationally.

Fourth, the NDIS is building the best whole of population and longitudinal database on disability in the world with data on functional impairments (not just primary disability); the goals of NDIS participants, funding allocations; expenditures; and, outcomes. This data is now being linked to other datasets including social security, tax, employment, health, education, housing and justice data through a new enduring National Disability Data Asset. The NDIS is therefore at the centre of the establishment of a unique foundation for world-leading disability research. To build on this foundation, governments are also providing funding to pilot a National Disability Research Partnership, which is being led by MDI.

The NDIS is therefore a large and complex reform and, inevitably, there are and will continue to be operational and implementation issues. It is why we needed a trial phase. It is why through the last seven years the management and governors of the Scheme have had to listen, learn, refine and deliver. I have always seen the NDIS as a 10-year project and this remains my assessment of how long it will take for the NDIS to fully achieve its bold vision.

My interest in what is now the NDIS began in 2006. I was then the chairman of a large disability organisation and it was clear that people with disability had large and growing unmet needs for support, that people with disability were not able to maximise their potential or engage fully in work and the community and while governments had visionary ‘Disability Plans’, there was never the resources to make these goals and aspirations real.

However, at that time the environment for any disability reform, let alone large and transformational change, could not have been less propitious.

The disability rights movement had lost impetus since the reforms of the 1980s and the disability sector had become balkanised as groups were forced to compete against each other for increasingly scarce funding.

Australian governments were also totally disinterested in disability reform and so when the campaign for the NDIS began it did not have any support or standing with governments or bureaucrats.

Yet, by 2013, the disability sector would unite, the mandarins of the Commonwealth and state governments would be won over, the support of all governments and all political parties would be secured, and reform would be established.

The fact that this outsider of a policy idea was able to fight its way to the front of the national conversation demonstrates the power of individuals to improve public policy and society.

Leadership, vision, unity, language, economic evidence and sustained community engagement were the essential ingredients which led to the NDIS.

Leadership is critical to all reforms and especially large and complex reforms. In the case of the NDIS, visionary and united sector leadership was achieved through the creation of a new peak body, the National Disability and Carer Alliance.

The Alliance brings together people with disability, carers and disability service providers, in a world-first commitment to shared leadership of the sector.

The idea for the Alliance was Rhonda Galbally’s, born out of a lifetime of advocacy on behalf of people with disability, and it remains a world first. Without it we would not have the NDIS.

The NDIS was also a unifying idea. It ended decades of schism within the disability sector because it provides support based on need, in contrast to the cruel lottery of the old system where support was based on disability type, cause, age or where people lived. The NDIS became the catalyst for the disability sector not just to unite, but to speak with one voice.

Language and a reframing of disability were critical to building public support for the NDIS. The description of the old disability system as “broken” created a burning bridge for inevitable reform.

The emphasis on the word “insurance” in the name of the NDIS made it relevant to all Australians, not just those with disability, because none of us know when we or our children or grandchildren might acquire or be born with a disability.

Meanwhile, the campaign’s name, “Every Australian Counts”, alerted the community that some of Australia’s most vulnerable citizens were shut out of mainstream life.

Economic evidence and analysis is the basis for public policy development in Australia. With that in mind, the NDIS framed disability primarily as an economic issue, not just a social policy or human rights issue.

The Shut Out and Disability Investment Group reports in 2009 helped to set the scene.

Then, in 2010 and 2011, following exhaustive examination and more than 1,100 submissions, the Productivity Commission, Australia’s pre-eminent economic research think-tank, concluded that the old disability system was “underfunded, inefficient, fragmented and gives people with disability little choice and no certainty”, that the economic benefits of the NDIS would far outweigh its costs and that over time it would add close to 1 per cent to GDP.

John Walsh was seconded to the Productivity Commission for that Inquiry and his deep knowledge of disability and actuarial expertise were invaluable.

I first met John, in 2006, because I wanted to know whether he could cost a scheme for all people with severe and profound disabilities. His answer was direct: “Of course, he said, once I get the data!”

During the Productivity Commission Inquiry and following its Final Report, the Every Australian Counts campaign elevated disability from a social and economic issue into a political issue. It engaged with all community sectors, especially those that might have been hostile or sceptical, in order to build their understanding of the economic case and move disability from the margins to the mainstream of public discourse.

We were fortunate to recruit Kirsten Deane to the Every Australian Counts Campaign, which she has now championed for a decade. Kirsten had been both Co-Chair and Deputy Chair of the National People with Disability and Carer Council, the principal advisory body to the Commonwealth Government and she had personally largely written the ‘Shut Out’ report. She is also the mother of a child with Down Syndrome and so brings to the role lived experience and a passion for disability reform.

Every Australian Counts was, and in fact still is, a grassroots and social media campaign, which used technology smartly. People with disability told their personal and family stories – stories that were authentic, credible, personal, powerful and shocking.

Their stories resonated and within two years the Campaign had more than 150,000 supporters.

Prominent reporting and supportive editorials in key parts of the mainstream media added to community understanding and very quickly Australians without direct knowledge of disability came to see the NDIS as equitable, decent and economically rational.

This culminated in support from 80 per cent of voters when in May 2013 the Commonwealth Government proposed an increase of 0.5 per cent in the Medicare levy to partially fund the NDIS.

Never before—or since—has a tax increase in Australia been greeted with such strong support.

The NDIS was also very fortunate that all of Australia’s federal and state political leaders and Disability Ministers came together to embrace its vision, making support for the NDIS multiparty and national.

This led to the enactment of the NDIS Act in 2013 and agreements between the Commonwealth and State and territory governments. This deep and wide commitment was essential, because it was clear from the start that the NDIS would take many years to implement.

The support of all political parties was therefore a key and enduring success of the Every Australian Counts Campaign, as the support of all governments for the NDIS has not wavered.

One helpful way, I have found, to think about the formation of the NDIS is through a Policy Triangle, which has at its apexes the policy context, content and process, with actors in the centre of the triangle. All of these components are essential to the policy reform process and must come together.

In the case of the NDIS, the key context was that before the introduction of the NDIS disability costs were rising at 7 to 8 per cent per annum. Year by year this was creating a demographic timebomb which was simply unaffordable for State governments which had the primary responsibility for disability expenditures before the introduction of the NDIS. Then in 2010, the establishment of the National Disability and Carer Alliance and the Every Australian Counts Campaign were community-led game changers.

The policy content was provided through the Shut Out Report and a report by the Disability Investment Group in 2009, the Productivity Commission Report on Disability Care and Support in 2011 and then reports from the NDIS Advisory Group to the Council of Australian Governments in 2012 and 2013.

Key processes included:

* the so-called 2020 Summit in 2008, which set out a future vision for Australia and which was when the NDIS first received public recognition,
* then Australia becoming a signatory to the UN Convention on the Rights of Persons with Disability and the referral of the NDIS to the Productivity Commission for study in 2009, and
* following the Productivity Commission Report, the establishment of the Council of Australian Governments NDIS Advisory Group, which embedded people with lived experience of disability in the policy process.

Several of the key actors are here today but in addition, I also need to mention the essential roles played by the Honourable Jenny Macklin, who was the Disability Minister from 2007 to 2013, the Honourable Bill Shorten, who commissioned the Disability Investment Group and continues to champion the cause of people with disabilities, and former Prime Minister, the Honourable Julia Gillard who committed to her government to establishing the NDIS, famously stating: “we will get it done” and she did, making the NDIS one of the signature reforms of her prime ministership.

We could not have created the NDIS without government support, but governments would never have created the NDIS without the leadership and passion for reform shown by people with disability, their families and carers. The NDIS is therefore, above all, a triumph of hope, inclusion and unity and demonstrates that ordinary citizens can create the perfect storm for transformational and enduring reform.