

Disability Reform: The Challenges and Opportunities¹

I would like to acknowledge the traditional owners of the land on which we are meeting and to pay my respects to their elders, past and present.

I would also like to congratulate National Disability Services for the leadership they have displayed in organising today's Summit and, in particular, for bringing together people with disabilities, advocates and carers, as well as many disability organisations from throughout Victoria.

Richard Dent, when setting the scene, at the outset of this Summit highlighted many of the challenges facing the sector and made a powerful case for change.

As we look forward and begin to craft a reform agenda, it is important to reflect on and draw strength from the rich history of the disability sector in Victoria because most if not all the organisations which are represented in this room were established because their founders bravely chose not to accept the status quo.

We need to rekindle their spirit of reform and, as Rhonda Galbally has suggested, in doing so, apply 21st century principles, which include people with disabilities and their carers.

Today's primary focus has been on the sustainability of service providers. If anyone ever doubted the importance of this issue we need look no further than the Global Financial Crisis. My background is in funds management and banking. Globally the severity of the financial crisis has been exacerbated because of bank failures. In contrast, in Australia, we have been relatively unscathed because our banks have remained strong and viable. Similarly if we want high quality disability services our organisations must remain strong and viable, too.

This is a point which we recognised at Yooralla some eighteen months ago and so Bryan Woodford, who was then the Chief Executive of Yooralla, and I arranged to

¹ Presentation to the launch of the National Disability Services (Victoria) *A Fair Go for All* Campaign, 1 July, 2009

meet informally with the Chief Executives and Chairs of a number of other disability organisations so that we could work closely with NDS on the Price Review. This group has become known as the Inter-Agency Group and has made an important contribution to today's recognition that government services are under-funded by around \$50 million per annum.

However, the reform agenda needs to go much further than organisational viability, because there is an overwhelming moral, social and economic case for disability reform.

We need to become champions and we need to build the broadest and deepest support base before the current challenges become overwhelming and turn into a full blown crisis.

In 2003, the latest year for which data is available, labour force participation rates for people with disabilities were approximately two-thirds the rates of participation for people without disabilities, ranking Australia 13th out of 19 OECD countries². In the same year the unemployment rate for people with disabilities was nearly twice the national average at 8.6%, compared with 5.0% for people without disabilities³. More recent Census data from 2006 suggests that the gap has since widened further

Amongst carers who provide informal care full time and are in receipt of Carer Payment only 11 per cent 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 work⁴. This is a huge cost to society.

² Australian Institute of Health and Welfare (AIHW), Disability in Australia: trends in prevalence, education, employment and community living, Bulletin 61, June 2008

³ *ibid*

⁴ In 2007/08 18,000 people ceased receipt of Carer Payment and 53% moved onto other forms of government income support

Amongst families providing care and support the Australian Institute of Family Studies⁵ has reported that:

- Sixty per cent (60%) of carers provided care for more than 100 hours per week;
- Thirty per cent (30%) 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; and,
- 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.

The current dependence on informal carers therefore cannot be sustained and reform is therefore inevitable.

In essence, the cost of caring for people with disabilities represents a very large unfunded liability.

In the years ahead, the size of this unfunded liability will grow significantly due to: increasing incidence of disability at birth⁶; increasing numbers of people with acquired brain injuries; people with disabilities living longer and increasingly outliving their parents; changing attitudes to work amongst women which is resulting in increased labour force participation; and, a shift towards more single person households which is reducing the capacity of the community to provide informal care

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 share of disability costs which will need to be paid for by governments.

⁵ B Edwards, D J Higgins, M Gray, N Zmijewski and M Kingston, *The Nature and Impact of Caring for Family Members with a Disability in Australia*, 2008

⁶ Victorian Birth Defects Reports and other sources

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 and unsustainable burden on taxpayers. This led to the development of compulsory superannuation.

As some of you are aware I and others have been promoting the idea of a National Disability Insurance Scheme, because we need a national solution, not just a Victorian solution, to address the current shortfalls in services, inefficiencies and inequities.

An NDIS would insure all people with permanent disabilities acquired before the age of 65, without reference to cause or fault and would treat people equally based on their needs.

Disabilities to be covered by the Scheme would include catastrophic injury, intellectual, physical, and behavioural disabilities, mental illness and the consequences of progressive medical conditions such as motor neurone disease and multiple sclerosis.

Benefits would include care, accommodation, therapy, support and community access. Services would be centred on individual needs and choices and reflect changing needs over the life-course.

Early intervention, which we know has significant benefits, would be a top priority, because it leads to lower costs in the long term. Similarly, aids, equipment and home modification needs would be met on a timely basis and would reduce medium and long term costs.

Families would be expected to fulfill normal age-appropriate caring roles and choose to work or to provide informal care, as for families without disabled members.

The funding would be through a Medicare-type levy or general revenue because disability is a risk that can affect anyone and so a general community charge based on capacity to pay is the most appropriate way to pay for the Scheme.

Since the idea of an NDIS was first mooted at the 2020 Summit last year and adopted as one of its Big Ideas, it has gathered considerable momentum and shows how small beginnings, like today, can start to create forces for significant change.

Addressing the National Press Club on 1 April this year, less than 12 months after the Summit, the federal Parliamentary Secretary for Disabilities, Bill Shorten, described the NDIS proposal as “a simple yet visionary and exciting idea”⁷.

There are also signs of rare bipartisan political agreement emerging. The deputy chair of the Better Support for Carers’ Inquiry, which reported on 1 May, Western Australian Liberal MP Judi Moylan, called for a detailed analysis of an NDIS⁸.

Amongst senior public servants, Dr Jeff Harmer, the Secretary to the Department of Families, Housing, Community Services and Indigenous Affairs, in his recent Pension Review stated:

“... 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.”

Mr Brendan O’Reilly, who retired as Director General of Disability Services in New South Wales in February has called for the introduction of an NDIS within four years. Privately, others in government are also very supportive.

Within the disability sector, the National Disability and Carers Alliance has been formed, bringing together the Australian Federation of Disability Organisations, Carers Australia and National Disability Services, and its first priority is the introduction of an NDIS.

⁷ Hon Bill Shorten MP, Right to an Ordinary Life, National Press Club, 1 April, 2009

⁸ House of Representatives Standing Committee on Family, Community, Housing and Youth, Report on the inquiry into better support for carers, April, 2009, p258

The Alliance has been strongly supported by Rhonda Galbally, who I would like to acknowledge today as a real champion of an NDIS, as well as people with disabilities. As a champion of the NDIS she is using all her considerable connections and influence to promote the Scheme and so I would like to warmly thank her and say: Australia needs more Rhondas.

Other supporters now include The Australian which has written an editorial in support of an NDIS, Alan Jones who has been promoting the Scheme on Sydney radio and the recent ACTU Congress which passed a resolution in favour of an NDIS.

So, from the first public airing of the idea of an NDIS 15 months ago, there is now support for this idea right across the political spectrum, within governments and in the broader community. Of course the challenge is to broaden and deepen this support and to turn the NDIS into a reality. The next step is a detailed feasibility study because this is a complex reform, which Bill Shorten has correctly said “would turn our current system of disability services on its head”⁹.

We need your support for an NDIS and so I would urge you to go to the website www.ndis.org.au and register your organisation or individually as supporters if you have not already done so. The website will soon be upgraded to a campaign site and a petition is already circulating which we hope will be signed by 1 million people.

In closing, some of you may have read the harrowing report in The Australian last Friday about Mr Frank Harton, a 76 year old father, who will now not be forced to stand trial for the attempted murder of his 47 year old intellectually disabled son, Chris. Mr Harton feared that when he died Chris would be unable to cope and would become a burden on his family and society and so he tried to shoot him¹⁰.

We know that there are thousands of other parents with children with disabilities who live in fear of what will happen to them when they die. We know about the equipment shortages. We know that early intervention services are often sub-optimal. We know that the current system is a lottery.

⁹ *ibid*

¹⁰ Verity Edwards, The Australian, 26 June, 2009

We now all need to work together to become champions of disability reform.

Thank you.

Bruce Bonyhady¹¹

¹¹ Bruce Bonyhady is Chairman of Yooralla and is a Member of the Disability Investment Group established by the Parliamentary Secretary for Disabilities and Children's Services, the Hon Bill Shorten. He has three children, two of whom have disabilities.