



## Adequate Support for People with a Disability<sup>1</sup>

Bruce Bonyhady

**On April 6, 2008** *The Sunday Age* reported:

True love never dies. But, in a sense, one of Melbourne's most moving little love stories ended on Friday. Kenny Morrison, 61, passed away last Saturday and was farewelled on Friday, leaving behind his devoted mother, Gwen [aged 92]. And that's the way Gwen always wanted it. Fourteen years ago, when I first met Gwen and Kenny, she told me she couldn't die before him. From the time Kenny was born — on January 21, 1947, with Downs syndrome — Gwen had dedicated her life to him. From the day her husband Arthur died, in March 1971, she had done so alone. 'Staying alive, that's my aim and my necessity,' she said. 'My main object is to keep alive for him as long as I can, because he's on his own after that.'<sup>2</sup>

Kenny and thousands of other people with disabilities in Australia fall through a huge gap in our social services network, because their injury or disability is non-compensable. Because of this, individuals with a disability struggle below the poverty line, or their families, like Gwen, are expected to provide care until they die or otherwise cannot continue. They endure because there is no alternative; or, in the case of family members, because they feel it is their duty and responsibility, despite the huge costs to their health and wellbeing. 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 such as workers' compensation.

### **National Disability Insurance Scheme**

Now is the time to extend these social insurance models by introducing a fully funded no-fault National Disability Insurance Scheme (NDIS). A NDIS would rank alongside Medicare and compulsory superannuation as a visionary economic and social reform for the benefit of all Australians.

With each of us at risk of experiencing a disability and the number of Australians with a disability increasing all the time, this issue affects every Australian, today and in the future. In April 2008, the 2020 Summit recognised the potential benefits from a National Disability Insurance Scheme and recommended it to the Government as a Big Idea. It is time to cement a National Disability Insurance Scheme at the heart of support systems for people with disabilities and their carers; to give essential security to all Australians.

### **Lost decades**

- In 1976 the United Nations proclaimed 1981 as the International Year of Disabled Persons (IYDP). The theme of IYDP was equality and full participation. In Australia IYDP was widely celebrated, and at the time people with disabilities and their families saw this landmark as the dawn of a new era.
- In 1987 the *Disability Services Act* was proclaimed. A clear object of the Act was 'to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services'.
- In 1992 the first Commonwealth States and Territories Disability Agreement (CSTDA) was supposed to set clear standards for meeting the needs of people with disabilities. However, the outcome from it and subsequent CSTDAs has been a shuffling of responsibilities between the

Commonwealth and the States, without clear accountability, and a mixture of service models.

- In July 2008 the Commonwealth Government signed the UN Convention on the Rights of Persons with Disabilities, but this was not accompanied by any changes in current arrangements and services to ensure that the rights in the Convention would be achieved either now or in the future.

Today, there are significant differences between the levels of ongoing care and support that are available through different parts of the social security system, medical and health insurances, workers' compensation, third party car insurance and public liability insurance. These inconsistent arrangements are inequitable at any point in time and over time, leave uninsurable risks and cause great hardship, anxiety and fear for those who fall through the safety net.

### **Future challenges**

In essence, the cost of caring for people with disabilities represents a very large unfunded liability. It must be met directly by families, friends or the community through government expenditures. To date these problems have been analysed in a rights framework, including the Commonwealth Government's recent decision to sign the UN Convention on the Rights of Persons with Disabilities without adding to the resources available to people with disabilities, or a welfare framework has been applied, leading to demands for more support, without any discussion of how these needs should be funded.

In the next 15 to 20 years, the size of this unfunded liability will grow significantly due to increasing incidence of disability at birth<sup>3</sup> (older mothers, IVF and increased survival rates among very low birthweight babies), increasing numbers of people with acquired brain injuries (due to alcohol and substance abuse, including foetal alcohol syndrome, and domestic and street violence), people with disabilities living longer, and others acquiring disabilities as they grow older. Based on population projections, Australia's population will increase by around 3 million people over the next 15 years and

almost two in every five of these people will have or acquire a disability.<sup>4</sup>

At the same time, the number of informal carers per head of population is expected to decline sharply as older carers pass away or become too infirm to look after their adult children. Among young families the capacity to provide care for a disabled child is declining, because for more and more families both parents need to work to pay the mortgage and meet other necessary expenses. (According to the National Centre for Social and Economic Modelling the number of principal carers for every 100 older persons needing informal care will fall from 57 in 2001 to 35 in 2031<sup>5</sup> and, according to Access Economics, the replacement value of informal care, Australia-wide, is \$30.5 billion annually.<sup>6</sup>)

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 costs of disability, which under present arrangements will add significantly to government outlays. We need to plan ahead before the current unmet and undermet 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 burden on taxpayers. This led to the development of compulsory superannuation.

### **From welfare to opportunity**

The current approach to supporting people with disabilities is based on an outdated welfare model. It provides services at a point in time rather than recognising that the needs of people with disabilities change over their life course. It is focused on minimising costs in the short term rather than minimising costs and maximising opportunities over a lifetime. It is also poorly integrated with other support structures and the responsibilities of the Commonwealth and the States are unclear.

As a result people with disabilities are amongst the most marginalised in Australia as illustrated here.

- 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.<sup>7</sup>
- The unemployment rate for people with disabilities seeking work was 8.6% in 2003 compared with 5.0% for people without disabilities.<sup>8</sup>
- Disability Support Pension (DSP) recipients are amongst the poorest groups in Australia and in 2007 the recipients had spent an average of 8.7 years out of the past 10 years on the DSP.<sup>9</sup>

According to the Australian Institute of Health and Welfare (AIHW), using conservative estimates, there were 23,800 people with disabilities looking for accommodation and 9,600 seeking community access in 2005.<sup>10</sup> Since then, unmet demand has certainly grown.<sup>11</sup> The absence of more reliable estimates of unmet and under-met needs is symptomatic of a deeply flawed approach: Disability policy is focused on ‘managing’ (minimising) demand rather than lifting the horizons of people with disabilities and their families by meeting their needs and creating opportunities.

Amongst families providing care and support to loved ones with non-compensable injuries the Australian Institute of Family Studies<sup>12</sup> estimates that:

- 60% of carers provided assistance to a person with a disability for more than 100 hours per week.
- 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.
- 51% of female carers and 31 per cent of males had been depressed for six months or more since they started caring.

The current mix of ad hoc policies to support people with disabilities should be replaced with an integrated approach,

embracing income support, employment strategies and additional support through a NDIS, which recognises the specific needs of people with disabilities.

The Commonwealth Government has committed to undertaking a review of pensions, including the Disability Support Pension. It should be adjusted so that people with disabilities are no longer locked in poverty. The Commonwealth Government is also undertaking a review of employment strategies for people with disabilities. The barriers to employment of people with disabilities should be removed. The inclusion of people with disabilities in the community should also be supported through accessible housing, accessible public spaces and accessible transport.

However, the most pressing need is a shift from the current crisis-driven welfare approach, in which services typically only are made available to families in crisis, to a planned approach that builds, nurtures and maintains social capital through the provision of support for people with disabilities and their families, so that they can sustain self and informal care rather than being left to cope with minimal support until they collapse.

The idea of disability insurance is built on the models used for workers' and accident compensation including, most importantly, the analyses by Meredith, Beveridge and Woodhouse.<sup>13</sup> Among economists, Kenneth Arrow, who later received the Nobel Prize for Economics, analysed individual and community welfare in the face of uncertainty, proving that there is a net social gain from taking out insurance for medical costs and the costs of disability.<sup>14</sup> More recently, among social policy researchers such as Gunther Schmid in Germany and Brian Howe<sup>15</sup> in Australia, some new thinking has emerged regarding risks and transitions through the life cycle. They argue that the structure of social policy needs to shift from support at a single point of time and a static safety net that can leave people close to poverty or in crisis for years, to a more dynamic construct that supports personal development and new opportunities. In 2005, John Walsh and others undertook a detailed actuarial analysis of a long-term care system for

people who are catastrophically injured.<sup>16</sup> It recommended a no-fault insurance scheme for all people who are catastrophically injured and provided an estimate of the costs of fully funding the scheme. Now it is time to combine the analyses from these sources and establish a National Disability Insurance Scheme, because such a scheme would provide the support essential for people with disabilities and their families and bring peace of mind to all Australians.

In April 2008 a submission to the 2020 Summit recommended:

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.<sup>17</sup>

This idea was supported at the Summit, and the Final Summit Report recommended that the government:

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.<sup>18</sup>

The models for a NDIS already exist in Australia, as there are already fully-funded no-fault insurance schemes to meet the needs of people injured in the workplace in New South Wales, Victoria, South Australia, Northern Territory and the Commonwealth, and in car accidents in New South Wales, Victoria and Tasmania. There are also international examples of disability insurance schemes, such as the Accident Compensation Commission in New Zealand. The advantages of these schemes are very significant. First, with an insurance model the families of people with disabilities can have confidence that the needs of their family member will be met, reducing stress and risks of family breakdown. Second, a lifetime approach to care ensures that early intervention, therapy, accommodation and equipment/home modifications are available immediately following diagnosis or injury, leading to

better and lower cost long-term outcomes. Third, active case management facilitates as normal a life as possible and minimises the risks of over-dependence on publicly funded support.

These outcomes, all of which have been achieved under the Transport Accident Commission and WorkCover schemes in Victoria, can be contrasted with cases in which people with disabilities receive lump sum insurance payouts. In New South Wales a recent study shows that within 20 years 95% of those accident victims who are lucky enough to receive lump sum payouts start accessing government-funded disability support.

A national insurance-based model would also be much more equitable than present arrangements, where there are large differences between states. There are also major inequities between the few who have access to multi-million dollar payouts and the majority who receive very little support, and between the treatments of identical injuries depending on how they are acquired. For example, a brain-injured car accident victim in Victoria is covered, while a brain-injured physical assault victim is not. The contrast with a National Disability Insurance Scheme could not be starker: such a scheme would be equitable and enable people with disabilities and their families to be in control, make choices and plan their lives with confidence. A universal National Disability Insurance Scheme would need to be funded from a number of sources and would require close cooperation between the Commonwealth and the States. However, the benefits from a more coordinated and national approach cannot be underestimated.

### **The solution**

A National Disability Insurance Scheme would include the following features.

#### *Eligibility:*

- all people with permanent disabilities acquired before the age of 65, without reference to cause or fault are treated equally based on needs



- needs to be assessed using functional (intellectual, physical and behavioural) impairment tests. (It is expected that all people with profound or severe disabilities would qualify, while those with moderate or mild disabilities would qualify depending on their specific needs.<sup>19</sup>)
- as people with disabilities age, their requirements for assistance to be dovetailed with the aged care system to allow them to age in place.

*Benefits:*

- care, accommodation, therapy, support and community access (not income support, which would continue to be provided through the pension system)
- services based on functional impairment and centered 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.

*Role of families:*

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

*Funding arrangements:*

- funding through a Medicare-type levy/general revenue because disability is a risk we all face and so a general community charge based on capacity to pay is the most appropriate.
- fully funded or at least partially funded scheme.
- existing workers' compensation, motor vehicle accident and medical indemnity insurances all to continue as no-

fault or to be converted to no fault, with separation of compensation from legal actions for negligence or culpable actions.

*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
- governance framework to monitor and manage scheme assets, liabilities and data collections to optimise scheme performance
- monitoring of Scheme usage to underwrite responsibilities as well as rights
- independent review/appeals process.

*Other features:*

- research and prevention strategies to reduce long-term costs (like TAC).

## **Conclusion**

Now is the time to implement a National Disability Insurance Scheme. This is a requirement for a mature and civilised society to enable adequate support for thousands of people with a disability. It would be a fair and compassionate solution for families and carers like Gwen Morrison, who could then look to the future with confidence rather than with dread and despair.

## **Endnotes**

- 1 This chapter draws on a paper written on behalf of Yooralla, Disability Services Australia and The Spastic Centre and submitted to the Commonwealth Government in December 2008 in response to a request for contributions to the development of a National Disability Strategy. See [www.natdis.com.au](http://www.natdis.com.au). This paper (and the earlier version) draws heavily on Bonyhady, B.P., and Sykes, H., *Disability reform: From crisis welfare to a planned insurance model*, April 2008, which was submitted to the 2020 Summit.

- 2 Gary Tippet, *The Sunday Age*, April 6 2008, Story ends as it began — with love.
- 3 Victorian Birth Defects Reports and other sources.
- 4 Estimates calculated based on ABS Disability Australia, 2003, ABS Disability, Ageing and Carers, Australia, 2003, ABS Population Projections, 2004 to 2101.
- 5 National Centre for Social and Economic Modelling (NATSEM; 2004). *Who's going to care? Informal care and an ageing population*. Report prepared for Carers Australia.
- 6 Access Economics Pty Limited August. (2005). *The economic value of informal care*. Report prepared for Carers Australia.
- 7 Australian Institute of Health and Welfare (AIHW), Disability in Australia: trends in prevalence, education, employment and community living, *Bulletin 61*, June 2008.
- 8 *ibid*
- 9 Department of Families, Housing, Community Service and Indigenous Affairs, *Australia's Future Tax System Pension Review Background Paper*, 2008.
- 10 Australian Institute of Health and Welfare, Current and Future Demand for Specialist disability Services, June 2007.
- 11 See, for example, Coalition for Disability Rights, Call to Political Parties 2006 Victorian State Election.
- 12 Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., & Kingston, M. (2008). The nature and impact of caring for family members with a disability in Australia.
- 13 See Clayton, A., (2003), Some reflections on the Woodhouse and ACC Legacy, *Victoria University of Wellington Law Review*.
- 14 See Arrow, K. J., (1963, December). Uncertainty and the welfare economics of medical care, *The American Economic Review*, in which Arrow uses the term 'failure to recover' to describe disability.
- 15 Howe, B. (2007). *Weighing up Australian values*. Sydney, Australia: UNSW Press.
- 16 Walsh, J., Dayton, A., Cuff, C., & Martin, P. (2005, March). *Long-term care actuarial analysis on long-term care for the catastrophically injured*.
- 17 Bonyhady, B., & Sykes, H., *op cit*.
- 18 *2020 Summit Final Report*, Recommendation 6.6, May 2008.
- 19 Australian Bureau of Statistics, *Disability, ageing and caring user guide*, ABS 4431.0, 1998, defines profound, severe, moderate and mild disabilities based on the person's needs for assistance with common activities of daily life, such as showering or dressing,

BRUCE BONYHADY

moving around, housing and gardening or using transport, because of the person's disability.



**Bruce Bonyhady** is Chairman of ANZ Trustees Limited, President of Philanthropy Australia and Chairman of Yooralla. He was a member of the federal government's Disability Investment Group and the Reference Group to the Pension Review. He is a non-executive director with extensive experience in funds management and economics.