

## **WORKING TOWARDS A DIFFERENT FUTURE FOR CARING FAMILIES, SOME PERSONAL RELECTIONS, AND A SOCIAL AND ECONOMIC PERSPECTIVE<sup>1</sup>**

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.

What a day of hope to be talking to you about a different future for caring families and to give some personal perspectives.

Yesterday's announcement by the Prime Minister that the Commonwealth Government will now conduct a Feasibility Study into a National Disability Long-Term Care and Support Scheme or National Disability Insurance Scheme or NDIS, as it has been known up to now, represents a landmark on the road to fundamental reform of disability services in Australia. In one giant step the Prime Minister has taken disability services from the edge of social and economic discussions to the centre of his government's reform agenda and also added this issue to his government's COAG agenda.

It is an opportunity that every person with a disability and every carer should celebrate, whilst also recognising that a Feasibility Study is only a step towards reform; it is not reform in itself. As a Member of the Disability Investment Group which recommended that the Government should undertake a Feasibility Study into a National Disability Care and Support Scheme, I am delighted that the Government has accepted the principal recommendation in our Report.

My involvement in the disability sector began over 20 years ago, soon after my first child was born; before that I was like many Australians and knew very little about disability. Mike, who is now aged 25, has ataxic cerebral palsy and an intellectual disability. My youngest son, Greg, has the same disabilities, which means that the cause is genetic although we do not have a name for the condition. My third son, Simon, is between Mike and Greg in age and is both able and a great help to his brothers, my wife, Rae, and me.

When Rae and I first found out that Mike might have disabilities, we, and especially I, went through a period of grief, anger and fear, as each month seemed to bring more bad

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<sup>1</sup> Presentation to Carers Victoria, AGM, 24 November, 2009

news and uncertainty. Then, as his diagnosis stabilised, we began to feel fortunate because of Mike's bright smile and many endearing qualities.

Today, at a personal level, when I reflect on how having two sons with disabilities has affected my family and me, I feel a deep sense of good fortune and gratitude. Gratitude towards close and extended family, friends and the many professionals who have provided Mike, Greg, Rae, and me with extraordinary support over the past 25 years; wonderment that Mike and Greg create such positive energy in others; gratitude that Mike and Greg have taught me so much about valuing diversity, living in the moment and enjoying a full life on one's own terms; deep thanks that Mike, Simon and Greg are such close friends; and, a sense of great fortune that Rae and I have had the emotional resilience and financial resources that have enabled our marriage to endure and grow.

However, I am very aware how lucky Rae and I have been, how easily we could have found ourselves in a very different situation, how unfair the current system for supporting people with disabilities and their families can be. It is this deep sense of injustice that is driving me to seek lasting reform of disability services in this country.

As I consider what may be possible, I am inspired by Sister Faith, the Methodist Mission Sister, who in 1917 found a disabled girl in a cage in the backyard of her family home in Fitzroy. Her parents had left her there for the day so that they could go out and work. Sister Faith was not outraged by the actions of the parents, as they had no choice, but by a society that would allow this to occur. So she decided to raise civic concern so that disabled children could have access to education, therapy and a quality life. Her actions led to the formation of the Yooralla Hospital School for Crippled Children and an organisation that today touches the lives of 30,000 people with disabilities in Victoria each year.

Her towering vision and leadership and the contributions of the many thousands of volunteers and staff who have followed Sister Faith at Yooralla show that individuals can change the course of history. But today the welfare and charity model that Sister Faith and others pioneered and have worked so tirelessly to build is at breaking point across Australia.

The examples of the crises affecting people with disabilities, their families and carers are everywhere. One such story was told earlier this month in *The Sydney Morning Herald*, which reported on the harrowing choice—today’s Australia’s version of Sophie’s choice—that Anita Cain faced when her severely disabled son, Niall, was aged 15. She could continue to try and care for him and become totally exhausted and depressed or abandon him. In her words:

“I only got one weekend every two months respite...all I wanted was more regular, longer breaks, but they wouldn't find anywhere for Niall to go unless I officially abandoned him.”<sup>2</sup>

Some of you will have read the story in *The Sunday Age* on 6 April, 2008 about Gwen Morrison, who was then aged 92, her son Kenny and Gwen’s relief that Kenny had predeceased her. Gary Tippet 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. 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>3</sup>

Less than a year after Kenny’s death, Gwen passed away peacefully, knowing that her life’s work was complete.

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<sup>2</sup> Louise Hall, *The Sydney Morning Herald*, harrowing choice put a loving mother to the test, 3 November, 2009

<sup>3</sup> Gary Tippet, *The Sunday Age*, April 6 2008, Story ends as it began—with love

The role that families are expected to play, year after year and round-the-clock was poignantly told to the Prime Minister and his Cabinet colleagues in April last year when Catherine Murray, who cared for her profoundly disabled son Jonathon for 25 years, stood up at a Federal Cabinet community meeting in Penrith and said:

“I find it unconscionable that I would have to surrender my child, abandon him in the hospital, if it all got too much for me. Cradle to grave is a big ask, a really, really big ask.”<sup>4</sup>

I am telling these stories and personalising them not because such cases are unknown to you but because statistics neither do justice nor spark the outrage that is needed to ensure urgent reform. We are talking about real people, facing overwhelming challenges, who are at or past breaking point. It could be you or me.

Now, with yesterday’s announcement that the Government will undertake a Feasibility Study into a National Disability Care and Support Scheme there is an opportunity for transformational change. As the Prime Minister said last night, to describe this as “...a big idea is somewhat of an understatement. It would be a historic social reform.”<sup>5</sup>

The importance of such a Scheme goes beyond a simple change in funding models. What it does is shift the way we think about disability from being a welfare and charity issue to a risk and insurance issue.

For example we know that for every 1000 live births 2.5 babies will be born with cerebral palsy and eight will develop autism. Similarly, we know the incidence of deafness, blindness, motor neurone disease, multiple sclerosis and other disabling conditions. The likely severity of these conditions and the life expectancy of people with disabilities are also known. It is therefore possible, to calculate the lifetime costs, to collect premiums to meet those costs and to develop strategies to minimise those costs.

The Scheme would provide services for people with disabilities and assistance for carers, including:

- care, support and therapy based on needs

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<sup>4</sup> Catherine Murray, Question to Community Cabinet Meeting, Penrith, 16 April, 2008

<sup>5</sup> Hon Kevin Rudd, Prime Minister, Address to the National Disability Awards, 23 November, 2009

- case management to facilitate independence, maximise potential and plan transitions over the life course
- early intervention to maximise long term outcomes
- aids, equipment, technology and home modifications on a timely basis, and
- training, development and access to work to build self-esteem and reduce long term costs.

The Scheme would cover people born with disabilities or who acquired a disability through an accident or medical condition and mental illness.

The Scheme would be funded through either general revenue or a Medicare type levy because disability can affect anyone, anytime and these are the most efficient and equitable ways of funding such a scheme.

With a Long Term Care and Support Scheme, it is also likely that a range of private saving and investment strategies will emerge, to supplement government funded support. The Scheme could therefore be the catalyst for a new 'Three Pillar' support structure for people with disabilities comprising the Scheme, the Disability Support Pension and supplementary private savings and investment.

But more importantly, a National Disability Care and Support Scheme would enable people with disabilities and their families to make choices, to be in control, and to plan their lives just like anyone else. It would be consumer driven, as people with disabilities and their families would be at the centre. People with disabilities would get what they need when they need it and so eliminate a current source of huge stress and worry for people with disabilities and their carers.

A market place with a range of different services and service providers would develop. It would revolutionise how services are delivered and how they are funded.

It would give substance to Australia's recognition of the UN Convention on the Rights of Persons with Disabilities and help to fulfil the hopes that people with disabilities had in 1981, almost 30 years ago, when Australia celebrated the International Year of Disabled Persons.

It would allow people with disabilities and their families to plan ahead, rather than be crisis driven. It would invest in people with disabilities and recognise that families need support too. It would take account of each family's capacity to provide care and give them real choices, not Sophie's Choice as Anita Cain faced when she could no longer care for Niall. It would end the anguish of ageing carers such as Gwen Morrison who lived in fear that she might predecease Kenny.

The moral and social policy arguments for a National Disability Care and Support Scheme, as the current support system teeters on the edge of collapse, are therefore overwhelming. But it will be the economic case which determines whether the Productivity Commission Inquiry leads to the Scheme's introduction or other reforms, such as an additional compulsory superannuation levy or Denticare, receive priority. It is these arguments that will be tested and need to be honed, sharpened and confirmed between now and the Inquiry's Final Report in July 2011.

A National Disability Care and Support Scheme would meet four key economic criteria. It would be equitable, efficient, intergenerationally neutral and fiscally responsible.

First, equity. The Scheme would ensure people with a disability had access to services and support regardless of how, where or when they acquired their disability. This would be in stark contrast to the situation today where a few people have access to no-fault accident compensation schemes, a few more receive a lump-sum payout after years of draining litigation while the vast majority are forced to rely on family or friends and a complex service system that purports to ration services according to needs but is actually more akin to a lottery.

There are very different service levels across Australia. The States and Territories maintain different standards under the National Disability Agreement, while there are further differences at the local government level. All of these differences contributes to the current inequities and create insurmountable barriers to the mobility of people with disabilities and their families.

But it is not just inequity between people with a disability. It is also inequity between people with a disability and the rest of the population which underpins the case for reform.

Last year, the Federal Government undertook a Pension Review, which was chaired by Dr Jeff Harmer. It arose from deep concerns that people who are totally dependent on the single old age pension were living in abject poverty and that the treatment of couples and single pensioners was not equitable.

When Dr. Harmer and his team investigated the adequacy of pension arrangements they discovered, to their surprise, that people on the Disability Support Pension were in fact, on average, poorer than single old age pensioners, because the costs of disability are so high.

In the Budget last May the Government responded to the findings in the Pension Review by increasing pensions, including the DSP, by the most significant amount in over 30 years. This reform in the face of great fears about the effects of the Global Financial Crisis took courage and the Government deserves congratulations. However, at least of equal significance was the finding in Dr. Harmer's final report that the high costs of disability should not be covered through the pension system and that "a National Disability Insurance Scheme would be worthy of further consideration"<sup>6</sup>.

Second, efficiency. An insurance approach would lead to greater effectiveness and value for money for people with disabilities, families and government.

In the current welfare model there are enormous pressures to reduce costs in the short term. As a result there is very little attention paid to long term outcomes. This is true for both people with a disability and their families. Only lip service is paid to early intervention for people with a disability, despite overwhelming evidence about the long term benefits. As a result, many become more disabled than they should or miss out on opportunities. Carers are burnt out rather than nurtured and sustained in their roles.

In total, governments are spending around \$6 billion per annum on disability services and a further \$9 billion on the Disability Support Pension.

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<sup>6</sup> Department of Families, Housing, Community Services and Indigenous Affairs, Pension Review Report, Finding 23, February 2009

This is a lot of money, but in terms of outcomes the results are poor. People with disabilities have two thirds the labour force participation rate of people without disabilities and twice the unemployment rate. Each year fewer than 3 per cent of people on the Disability Support Pension come off the DSP without moving on to some other form of government income support. If this percentage could be increased by one percentage point per annum for 10 years, it would save close to \$1 billion in the 10th year, going a long way to offsetting the direct costs of a Long Term Care Scheme.

People with disabilities are also overrepresented in emergency hospital admissions, in the homeless population and in the judicial system, because they are not properly supported in the community. The Scheme would therefore save money in health and other social programs.

Many carers become disengaged from the labour force as a result of their responsibilities at home. Compared with the total population, carers are twice as likely to be in poor physical health, twice as likely to experience financial stress and nearly one half of all carers have experienced mental illness for six months or more since they became carers.

These poor outcomes for people with disabilities and their carers have high economic costs, as well as the obvious social costs.

In contrast, no-fault accident insurance schemes in Australia achieve much better outcomes through their focus on minimising lifetime costs and maximising lifetime opportunities. The lifetime insurance approach also creates a natural alignment of interests between the scheme management, people with disabilities and carers. Therefore while a National Disability Care and Support Scheme would add to costs in the short term, as it would meet current unmet needs, it has the potential to significantly reduce costs in the long term.

Finally, Intergenerational Neutrality and Fiscal Responsibility, which sound like a mouthful but are simple concepts. It is useful to think about disability in the context of the nation's balance sheet. On the balance sheet are assets, liabilities, potential assets and contingent liabilities, which depend on how the nation manages its resources and risks.

In terms of assets and liabilities, Australia sets aside almost no funds to meet the future costs of care for people with disabilities. Contrast this with superannuation – each year billions of dollars are set aside to meet future retirement incomes as Australia's population ages.

In terms of potential assets many people with disabilities have the potential and desire to work—if only they could get the chance. In terms of future liabilities, so long as we fail to provide appropriate early intervention, some of the current contingent liabilities will become actual liabilities, adding to future costs.

Looking ahead, that liability on the nation's balance sheet will grow as a result of increased incidence of disability at birth and people with disabilities living much longer. At the same time, the community's capacity to provide informal care is declining.

Therefore the total liability is growing. Most importantly the proportion of that liability that will need to be met by governments is also rising. As insurance schemes include provisions for future liabilities, one of the significant benefits would be that Australia would be able to strike an appropriate balance of costs between current and future generations. This is termed intergenerational neutrality by economists and is an important consideration in setting public policy.

Today, the costs of disability services are rising at 7 per cent in real terms each year, which will lead to a doubling of expenditures in just over 10 years. This is a staggering and unsustainable rate of increase. Australia can continue to ignore this growing moral, social and economic blight or invest and reform the disability support system by creating equity, driving efficiency and taking a long term view that will be intergenerationally neutral and fiscally responsible.

Last night the Mr Rudd, on behalf of his Government, signalled his clear intention to go down the reform path. It was an historic moment and one of great symbolism, because it occurred on the eve of the second anniversary of his Government.

Two years ago disability reform was not high on the Rudd Government's agenda. A year ago it was embroiled in battling the effects of the Global Financial Crisis. Today, because of the roles that Jenny Macklin and Bill Shorten have been playing in championing

disability reform within the Government, people with disabilities, their families and carers should celebrate, while also recognising the work that still needs to be done.

I would therefore urge you to do two things.

First, join with the National Disability and Carer Alliance and its members, Carers Australia, National Disability Services, and the Australian Federation of Disability Organisations, to provide even more united and stronger support for a National Disability Care and Support Scheme. Go to the website [www.ndis.org.au](http://www.ndis.org.au) and promote the Scheme amongst your family and friends and with your local MP.

Second, the Productivity Commission Inquiry will undoubtedly include public consultations, so there will be a chance for you to have your say. There could not be a better opportunity. Grasp it, because a National Disability Care and Support Scheme would be a transformational reform, a legacy economic and social reform, on the scale of the original Medibank scheme and compulsory superannuation with lasting major benefits people with disabilities, their families and carers.

Then we all will be able to say to Anita, Niall, Gwen, Kenny and Catherine and the hundreds, indeed thousands, of other carers and people with disabilities like them that their struggles have not been in vane; that their cases have led to a new approach to disability services based on risk, insurance and fair entitlements; that the welfare and charity model built by Sister Faith and others has been finally replaced by a new model which has been designed to meet the needs of Australians in the 21<sup>st</sup> century; that people with disabilities, their families and carers will finally cross what Bill Shorten has described as “the last practical barrier to civil rights in this country”<sup>7</sup>; and, that all Australians will have peace of mind, knowing that a huge gap in Australia’s social and economic policy framework has at long last been closed.

Thank you very much.

Bruce Bonyhady<sup>8</sup>

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

<sup>8</sup> Bruce Bonyhady is Chairman of Yooralla, President of Philanthropy Australia, and was a Member of the Disability Investment Group. Two of his three children have disabilities. The opinions in this speech are his own.