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**NATIONAL DISABILITY
STRATEGY**

FOR ALL

AUSTRALIANS¹

¹ This paper draws frequently on B P Bonyhady and H Sykes, Disability Reform: From Crisis Welfare to a Planned Insurance Model, April 2008, which was submitted to the 2020 Summit

EXECUTIVE SUMMARY

In April, 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.”²

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

“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.”³

This fully funded no-fault **National Disability Insurance Scheme (NDIS)** should become the centrepiece of the **National Disability Strategy**. Ranking alongside Medicare and compulsory superannuation, the scheme would be 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.

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 to government outlays.

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

Key features of the NDIS would be the universality of its eligibility criteria and the range of benefits to the individual with a disability through the appropriate funding of essential services. These benefits would include:

- care, accommodation, therapy, support and community access;
- case management to facilitate independence, maximise potential and plan transitions over the life course;
- early intervention as a top priority in the areas of therapy, education and accommodation support;
- aids, technology and equipment and home modification needs met on a timely basis; and,

² B P Bonyhady and H Sykes, *op cit*

³ 2020 Summit Final Report, Recommendation 6.6, May 2008

- training, development and access to work to build self-esteem and reduce long term costs.

THE ISSUE

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.’⁴

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 well being.

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.

Now is the time to extend these social insurance models by introducing a fully funded no-fault **National Disability Insurance Scheme (NDIS)** as the centrepiece of the **National Disability Strategy**.

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.

⁴ Gary Tippett, *The Sunday Age*, April 6 2008, Story ends as it began—with love

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.

THE RECOMMENDATION

It is time to cement a National Disability Insurance Scheme at the heart of the National Disability Strategy, to give essential security to all Australians.

THE 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 in Australia 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 on-going 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.

The National Disability Strategy could not be more timely.

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 birth⁵ (older mothers, IVF and increased survival rates amongst very low birth-weight 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 2 in every 5 of these people will have or acquire a disability⁶.

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. Amongst 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 2031⁷ and according to Access Economics the replacement value of informal care, Australia-wide, is **\$30.5 billion** annually⁸.)

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

FROM WELFARE TO OPPORTUNITY FOR PEOPLE WITH DISABILITIES

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.

⁵ Victorian Birth Defects Reports and other sources

⁶ Estimates calculated based on ABS Disability Australia, 2003, ABS Disability, Ageing and Carers, Australia, 2003, ABS Population Projections, 2004 to 2101

⁷ 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

⁸ Access Economics Pty Limited August 2005. The Economic Value of Informal Care. Report prepared for Carers Australia

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:

- 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, respectively⁹.
- The unemployment rate for people with disabilities seeking work was 8.6% in 2003 compared with 5.0% for people without disabilities¹⁰.
- 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 DSP¹¹.

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 2005¹². Since then, unmet demand has certainly grown¹³.

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 Studies¹⁴ estimates that:

- Sixty per cent (60%) of carers reported that they cared for a person with a disability 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.
- 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 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.

⁹ Australian Institute of Health and Welfare (AIHW), Disability in Australia: trends in prevalence, education, employment and community living, Bulletin 61, June 2008

¹⁰ *ibid*

¹¹ Department of Families, Housing, Community Service and Indigenous Affairs, Australia’s Future Tax System Pension Review Background Paper, 2008

¹² Australian Institute of Health and Welfare, Current and Future Demand for Specialist Disability Services, June 2007

¹³ See, for example, Coalition for Disability Rights, Call to Political Parties 2006 Victorian State Election

¹⁴ 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

The Commonwealth Government has committed to undertaking a review of pensions including the Disability Support Pension. It is strongly recommended that the Disability Support Pension should be adjusted in line with the age pension 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. It is strongly recommended that the barriers to employment of people with disabilities are 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 which 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 Woodhouse¹⁵. Amongst 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 disability¹⁶.

More recently, amongst social policy researchers such as Gunther Schmid in Germany and Brian Howe¹⁷ 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 injured¹⁸. 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 as the centrepiece of the National Disability Strategy, because such a scheme would provide the essential support essential for people with disabilities and their families and bring peace of mind to all Australians.

¹⁵ See Alan Clayton, Some Reflections on the Woodhouse and ACC Legacy, Victoria University of Wellington Law Review, 2003

¹⁶ Kenneth J. Arrow, Uncertainty and the Welfare Economics of Medical Care, The American Economic Review, December 1963

¹⁷ Brian Howe, Weighing Up Australian Values, UNSW Press, 2007

¹⁸ John Walsh, Anna Dayton, Chris Cuff and Peter Martin, Long Term Care Actuarial Analysis on Long-Term Care for the Catastrophically Injured, March 2005

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.”¹⁹

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.”²⁰

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 NSW, Victoria, SA, NT and the Commonwealth and in car accidents in NSW, 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 life-time 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 NSW 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.

¹⁹ B P Bonyhady and H Sykes, *op cit*

²⁰ 2020 Summit Final Report, Recommendation 6.6, May 2008

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 would be enormous.

THE SOLUTION

A National Disability Insurance Scheme would include these features:

Eligibility

- All people with permanent disabilities acquired before the age of 65, without reference to cause or fault and 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 needs²¹.)
- 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 centred 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.

²¹ 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, moving around, housing and gardening or using transport, because of the person's disability.

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, as the centrepiece of the new National Disability Strategy. This is a requirement for a mature and civilised society to enable adequate support for thousands of people with a disability. It would also be a compassionate solution for families and carers like Gwen Morrison who could then look to the future with confidence rather than with dread and despair.

November 2008