

Submission to the National Disability Strategy

# National Disability Insurance Scheme

A national disability strategy for all Australians

November 2008

# Supporters

The **National Disability Insurance Scheme** is endorsed by 48 of the largest and oldest disability and community services in Australia:

- Yooralla
- Disability Services Australia
- The Spastic Centre
- Northcott Disability Services
- House With No Steps
- Scope
- Community Connections Australia
- Greenacres Disability Services
- Cara
- Good Samaritan Industries
- Mai-Wel Group
- UnitingCare Disability
- Sunshine Homes
- The Centre for Cerebral Palsy
- MND (Motor Neurone Disease) Association of NSW
- MND (Motor Neurone Disease) Australia
- Help Enterprises
- SCOSA
- Job Placement Ltd
- Achieve Foundation
- Housing Choices Australia
- Eastern Disability Access Resource
- Berry Street
- ParaQuad NSW
- Carers Alliance Australia
- Oak Tasmania
- The Bedford Group
- Endeavour Foundation of Queensland
- E W Tipping Foundation
- Cerebral Palsy League of Queensland
- AFFORD, Australian Foundation for Disability
- Ability First Australia
- Novita Children's Services
- CP Australia
- Cootharinga Society of North Queensland
- Nadrasca
- Outlook
- Aspect
- Benevolent Society
- Karingal
- Redlands Bayside Disability Services
- Carpentaria Disability Services
- Somerville Community Services
- Nardy House
- TEAM Health
- Families Australia
- Life Without Limits
- Villa Maria

**Together, these not for profit organisations provide services to thousands of Australians with a disability each year.**

# Executive Summary

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>1</sup>

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.”<sup>2</sup>

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

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<sup>1</sup> B P Bonyhady and H Sykes, *op cit*

<sup>2</sup> 2020 Summit Final Report, Recommendation 6.6, May 2008

# 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.'<sup>3</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 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.

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.

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

# 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 birth<sup>4</sup> (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 disability<sup>5</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. 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 2031<sup>6</sup> and according to Access Economics the replacement value of informal care, Australia-wide, is **\$30.5 billion** annually<sup>7</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 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.

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<sup>4</sup> Victorian Birth Defects Reports and other sources

<sup>5</sup> Estimates calculated based on ABS Disability Australia, 2003, ABS Disability, Ageing and Carers, Australia, 2003, ABS Population Projections, 2004 to 2101

<sup>6</sup> 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

<sup>7</sup> Access Economics Pty Limited August 2005. The Economic Value of Informal Care. Report prepared for Carers Australia

# 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. 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, respectively<sup>8</sup>.
- The unemployment rate for people with disabilities seeking work was 8.6% in 2003 compared with 5.0% for people without disabilities<sup>9</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>10</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>11</sup>. Since then, unmet demand has certainly grown<sup>12</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>13</sup> 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 (51%) of female carers and 31 per cent (31%) 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.

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<sup>8</sup> Australian Institute of Health and Welfare (AIHW), Disability in Australia: trends in prevalence, education, employment and community living, Bulletin 61, June 2008

<sup>9</sup> *ibid*

<sup>10</sup> Department of Families, Housing, Community Service and Indigenous Affairs, Australia's Future Tax System Pension Review Background Paper, 2008

<sup>11</sup> Australian Institute of Health and Welfare, Current and Future Demand for Specialist Disability Services, June 2007

<sup>12</sup> See, for example, Coalition for Disability Rights, Call to Political Parties 2006 Victorian State Election

<sup>13</sup> 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 Woodhouse<sup>14</sup>. 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 disability<sup>15</sup>.

More recently, amongst social policy researchers such as Gunther Schmid in Germany and Brian Howe<sup>16</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>17</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 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.

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<sup>14</sup> See Alan Clayton, Some Reflections on the Woodhouse and ACC Legacy, Victoria University of Wellington Law Review, 2003

<sup>15</sup> Kenneth J. Arrow, Uncertainty and the Welfare Economics of Medical Care, The American Economic Review, December 1963

<sup>16</sup> Brian Howe, Weighing Up Australian Values, UNSW Press, 2007

<sup>17</sup> 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.”<sup>18</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>19</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 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.

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.

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<sup>18</sup> B P Bonyhady and H Sykes, *op cit*

<sup>19</sup> 2020 Summit Final Report, Recommendation 6.6, May 2008

# 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 needs<sup>20</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 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.

## 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).

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<sup>20</sup> 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.

# 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

# Appendix

People with a disability and their families have expressed their support for a National Disability Insurance Scheme at [www.natdis.com.au](http://www.natdis.com.au)

A selection of comments:

## **KATHY POMPETTI**

### **Biggest issues:**

Constantly having to source, apply to and prove eligibility for new services, then hitting HUGE WAITING LISTS!!! I cannot access enough support and feel like I have to fight every step of the way.

### **How my life could be changed by a NDIS:**

Having services that could be accessed as I need them would make a huge difference. It would mean proving eligibility once and no more waiting lists. Life would be sustainable in the short and long term - which is very different to my foreseeable future at this point.

## **SHELLEY VAN DER WERFF**

### **Biggest issues:**

Ongoing challenges associated with accessing people who can help us into each phase of my daughter's life in which her disability impacts. This often requires resources of money and a central point to visit.

### **How my life could be changed by a NDIS:**

Peace of mind that as my daughter ages that she can be adequately supported with finances and other resources to help her through life especially when I am no longer around!

## **SALAAM CAIRNS**

### **Biggest issues:**

I am a single mother with a 17 year old boy with several disabilities, trying to give my boy all the best opportunities in life that I can. We live in Sydney with no relatives to help me or my son. I work five 12 hour days a week so I can afford him the best education and therapy (which is endless), in an effort to one day see him become an integral part of the community and independent. Everyday I worry who will care for my son if something happens to me???

### **How my life could be changed by a NDIS:**

The NDIS will help to keep all my son's information in one basket, instead of running around lost, hoping that each time you make an appointment that person will have the knowledge to help. To be able to have one case worker that is familiar with my child, me, our home/work situation, therapies, our goals and aspirations, hopes and dreams would be fantastic. Also the financial benefit would help me to reduce my working hours, therefore enabling me to teach him valuable life skills like cooking, ironing, banking. All the things my son needs to become independent.

## **ANDREW**

### **Biggest issues:**

The lack of access to adequate respite facilities and the concern about our ability to provide long term care and the costs associated.

### **How my life could be changed by a NDIS:**

Although all brain injuries are different, case studies have shown that most recovery occurs within the first five years after the incident. Without funding, my son cannot expect to attain the rehabilitative therapies he requires to attain any degree of independence.

With services and equipment available, we could look forward to knowing that we had done everything we could for our loved one. So much of the energy spent and emotions we experience now are related to fighting for a more equitable funding model. I would like to be able to redirect that towards caring for my son first hand knowing that we were doing the very best we could for him.

## **THEA**

### **Biggest issues:**

Family stress. Marital tension. Respite needs. Long term accommodation. Frustration with long waiting lists on the Special Needs Register at Victorian DHS.

### **How my life could be changed by a NDIS:**

To have some more respite resources and options for future long term accommodation for my young adult son with a disability.

## **FIONA**

### **Biggest issues:**

The choice between financial ruin as we fund all our teenage son's physical, OT, cognitive therapy, equipment, home modifications, wheelchair van, etc., paid for by dipping into what's left of super and borrowing against our mortgage OR not paying for any of those things and knowing the government/agencies won't pay for any of them either. We could then survive financially but would condemn our son to low quality life, no rehab, no prospects for future development, learning or potential to earn his living as an adult. Great choice for a 21st century wealthy democracy!

### **How my life could be changed by a NDIS:**

Australia has the chance to be intelligent and actually plan and prepare for future changing needs instead of knee-jerk reaction throwing inadequate emergency funds at people. Government mindset could shift to INVESTING in all Australians to give best possible support to become independent, productive, socially connected citizens rather than financial burdens. And parents could face their own deaths not worrying whether their child with disability can survive without them.

## **CARMEL**

### **Biggest issues:**

Our profoundly autistic son is 12 years old and living in respite accommodation. I have nothing but praise for all the people who have helped us since we had to make the decision to relinquish him, as we could no longer provide him with the care and support he needs.

There are many children in his situation, taking up respite beds - thus denying other families the help they need in order to carry on just a bit longer.

WHY is there no permanent accommodation for relinquished children under 18?? My son's profound autism means all the transfers between respite houses are very distressing for him. This causes behaviour which is very hard to manage.

**How my life could be changed by a NDIS:**

My son needs secure permanent accommodation with regular caring staff 24 hours a day, every day (including public holidays). The respite staff are frustrated that this is not available, as it is placing an extra load on them.

**BARB****Biggest issues:**

We have my vision impaired mother in law of 86 years living with us. She resists supports because she is terrified of any form of assessment. I have to look after her needs.

We have an 8 year old with complex needs, developmental delay, CP and epilepsy. He is a truly unique little man. He is the height of an 8 year old but has no idea of danger and so we have to create a prison of our home to keep him safe.

We also have a 13 year old with DS. He is able and delightful but needs to look forward to a future of promise. He desperately wants to be treated as "normal".

**How my life could be changed by a NDIS:**

Mum may decide to access services because they were free.

The 8 year old would have access to new wheelchairs as required, we could access help to make our home safe for him. We could get respite care as required.

The 13 year old could join more sports groups and maybe the costs associated with Special Olympics could be reduced. He loves sport so much. He could get glasses that were designed for kids with DS but are only available from the US. We might even be able to afford large print books for him. He loves to read but generally finds the print too small.

We are a single income family, for obvious reasons, and just the nutritional supplement for the 8 year old costs \$30 a week. Medicines, shoes etc. It all adds up.

**RICHARD COXSEGE****Biggest issues:**

The lack of access to adequate respite facilities and the concern about our ability to provide long term care and the costs associated.

**How my life could be changed by a NDIS:**

It would assist by reducing the financial burden but more importantly the stress and worry associated with the inability to access the services and equipment at present.

**JUDITH****Biggest issues:**

Getting access to funds for urgently needed equipment. When I require it, NOT 2 YEARS LATER!

**How my life could be changed by a NDIS:**

It would allow me to plan for the future and not wishing for equipment I cannot afford.

## **SAM**

### **Biggest issues:**

As a person with a disability, the biggest challenges are gaining access to funding for equipment and other needs that would more easily allow me a sense of independence and equality both personally and in the workforce.

### **How my life could be changed by a NDIS:**

My life would be changed, as funding and waiting times for services would no longer be decisive factors in how I live my life.

## **BETH**

### **Biggest issues:**

I am a person with MS and looking forward to an uncertain future, particularly regarding equipment and appliances, as we are on a single income. Although we have modified our house a little there is much more we need to do, but we cannot afford it. We get so tired of fronting up to different agencies and having to tell our story over and over and over and then finding that they really have little to offer us. It has become all too hard.

On days when I am really ill my husband still has to go to work and I am left alone to fend for myself. Often this results in falls or other accidents related to lack of physical coordination. We are a long way from any services, being in New South Wales close to the Queensland border. We are often told to access Queensland services but when we try to do so we are told that those services have "over the border funding issues" and cannot help us. At the moment I am making do with a wheelchair that is too small for me. It is uncomfortable and painful to use. Fortunately I am not yet in the position of needing to be constantly in a chair.

I have been a productive member of the work force all my working life; up until about five years ago. I feel cheated that now, when I need help I cannot find it and I am treated as though I do not deserve it.

### **How my life could be changed by a NDIS:**

If we had a caseworker who knew us we wouldn't have to keep aimlessly trying new agencies and repeating our story. We would have one person who knew us and knew what we needed. I may be able to access some kind of in home respite for days when I am really ill. We could get the equipment that we needed and we would be able to plan for the future.

## **VANDA**

### **Biggest issues:**

Initially a lack of access to timely and effective services and support to assist us to take our son home from acute care.

Total lack of access to appropriate rehabilitation services due to severity of injury and perception that no gains would be made via rehabilitation.

Lack of appropriate respite services.

Difficulty with getting access to home modifications, vehicle modifications, aids and equipment generally.

### **How my life could be changed by a NDIS:**

More immediate access to supports and services that would have made the journey for our son and our family much easier.

Decreased financial strain on the family.

Access to a life time care system that takes away the uncertainty about the future would give us as parents peace of mind.

A life worth living post the health sector component of the journey.

## **MARIA**

### **Biggest issues:**

It is a life long process, some days are better, some days are worse. We have a intellectually disabled 15 year old son with autism and epilepsy. You never have a normal life, forever thinking of new plans, medical/behavioral/whatever works best so you can have some what of a normal life. From birth, until you find out what the problem is you are forever searching the internet, phoning for suggestions - most of the time people think you have become crazy or obsessed when they hear you talk or ask for help. We have spent thousands and thousands of dollars on therapy and professional help. There was no help available or some sort of instruction manual to lead us along the way.

### **How my life could be changed by a NDIS:**

To have some help along the way would be a great load off your family's stress and hardship. To lead you in the right direction to get a proper diagnosis and right support to start programs or interventions as early as possible.

We spend our lives looking after our children's needs and it would be a great support to know that we have help and we are not alone.

## **JANE**

### **Biggest issues:**

System complexity. Uncertainty. Networking to navigate the system. Identifying what opportunities are available - and how to access them. Knowing what you don't know - what is early intervention? What is appropriate and evidence based? Is the intervention best practice? How do I know I'm getting a good service? How, as a family do we maintain our quality of life? What does the future hold?

### **How my life could be changed by a NDIS:**

I would hope that a National Strategy moves beyond just providing free services and equipment. While this is essential to reducing the relentless stress put on families who struggle every day to maintain their quality of life the NDIS would (and should) have the capacity to help families navigate the system, access the best quality services available for their family member across the lifespan, and provide hope for the future.

## **ESTELLE SHIELDS**

### **Biggest issues:**

Our son has a severe intellectual disability. He is now thirty-one years old. The biggest issue for us is acquiring supported accommodation for him that is responsive to his needs and in our local area. At present there is no supported accommodation to be had, nor any hope of it in the future.

The service system that we have is unable to meet anything other than crisis situations, which means we must abandon him to the care of a government department that has no place for him in order to receive the service we must have. We have not yet arrived at this point although in the future it is inevitable that we will.

I am angry that families such as ours are forced into this predicament. I think it is a disgrace that our country lets its aged citizens care for its disabled ones. We are the parents who have worked harder than other parents, raising a disabled child, and when we get to retirement age, we are told there is to be no retirement, that we must keep caring unto death.

**How my life could be changed by a NDIS:**

If we had a National Disability Insurance Scheme we would have a funding base to provide the services that are so desperately needed. For us it would mean a planned, orderly, timely and age-appropriate transition for our son out of the family home and into suitable and local supported accommodation. It would mean that we could support him in this while we are still healthy and fit enough to do so. It would avoid the inevitable crisis that people with an intellectual disability now face: a crisis placement anywhere in the state after losing SIMULTANEOUSLY their primary carer and the only home they have ever known. This is a cruel and inhumane way of dealing with our most vulnerable people and unworthy of a civil and first world society.

**KAREN**

**Biggest issues:**

My biggest issue would be a lack of support and available funding for my 34yr old daughter who has Down syndrome. I am a single parent who has always cared for my daughter alone. Funding has always been very difficult to access due to the amount of people on the waiting list. I work full time to pay the mortgage and my daughter works as a supported employee and has respite care 2 days a week. She is able to earn a small amount from her supported employment but the cost of services takes more than she earns. As well the majority of services will not pick up and drop off at home so I have to transport her as well as pay fees. We have applied for funding packages many times but always miss out because there are others with more perceived high needs.

**How my life could be changed by a NDIS:**

My daughter would have more freedom to do things without being tied to me for transport, paying fees etc. It would give her the autonomy that most adults of 34 have. She would be able to choose to do the things she would really like to do without being limited by not having a carer/parent to take her or transport her to these outings. She could finally feel more like a 'grown up'.

For me I would have someone to take some of the incredible responsibility that I have always had.

**PAT TROWBRIDGE**

**Biggest issues:**

My daughter has Trisomy 21 (Down syndrome). She is a very capable young woman (19.5yrs old). We could have done with some kind of family services co-ordinator to have assisted with the transition from school, advocate in her school years and someone assist now with her future who understands disability, is not straight out of uni and doesn't leave in 6 months would have been a great help. Telling one's story over and over again is frustrating.

**How my life could be changed by a NDIS:**

Her future living situation is a concern for our family. I think she can live independently, but would need the weekly 'drop-in' to assist and monitor her finances, house keeping. My family are happy to do this, but she would be more open to support from someone outside of the family - always proving her independence to us.

More structured social groups on weekends would benefit her as so many of her friends aren't as independent as she is, so she doesn't get to see them as often as my other children see their friends. There are so many ways she would benefit from such a scheme - continuity, consistency and the 'one port of call'. The number of agencies and government departments is not only confusing for families, but a huge waste of time and tax payers' money. GREAT idea!

### **JACKIE WILLIAMS**

#### **Biggest issues:**

Trying to balance working many hours to pay for the therapy my daughter needs and having time free to actually give the therapy to her.

#### **How my life could be changed by a NDIS:**

Having financial support on an ongoing basis would mean an increased quality of life for us all.

### **PAMELA HARPER**

#### **Biggest issues:**

While we have no difficulty to cope with, we see the problems some friends and neighbours have, and we understand the stress of having to care for family members with a disability. A National Disability Insurance Scheme would appear to be a very good idea.

### **MEGAN**

#### **Biggest issues:**

My son is 23 years old and has an intellectual disability. The main problem we have now is, what will happen to him when we can no longer look after him? What people don't understand is that looking after people with a disability isn't going away. We are an ageing population and there are more disabled people coming, they may be children now but they will also be adults. At the moment there is no hope of accommodation for our son.

#### **How my life could be changed by a NDIS:**

The disability insurance scheme would hopefully give us, and other parents like us, hope of eventually having care for our children when we die. Other families won't have to live with the heartache and stress that we have been put through by governments who bury their head in the sand, hoping it will all go away.

### **SIMONE WARD**

#### **Biggest issues:**

Everything! Emotional and physical worries - both from a day to day perspective and a long term perspective. Massive financial concerns (as it is a severe physical disability). We need support for every single aspect of the person's life.

#### **How my life could be changed by a NDIS:**

Stop wasting our precious time spending our lives trying to access support (physical, emotional and therapeutic) and actually spend it helping the person with the disability.

## DAVID CARTER

### **Biggest issues:**

Lack of supported accommodation for my disabled brother when he finishes school.

### **How my life could be changed by a NDIS:**

Adequate supports and services for my brother, allowing him to fully participate in life socially, not permanently confined to the family home.

## DIANNE EVANS

### **Biggest issues:**

There are so many! Physically, emotionally and financially - we are being exhausted. We are more than willing to care for our daughter but we need help from the Government for our needs in the future. I am fearful that at some stage we will not be able to provide for her.

### **How my life could be changed by a NDIS:**

Give us peace of mind and provide for our future needs.

## CAROLINE, EDWIN FRANKS AND OUR THREE FUTURE VOTER CHILDREN

### **Biggest issues:**

A National Disability Insurance Scheme, such as that suggested by Mr Bruce Bonyhady, would enable us to secure equipment, aids, early intervention, home and car modifications, specialist services etc. based on our son's individual needs. In particular, we would be able to afford a safe school, timely and good quality behaviour intervention, community participation and a means for me to return to work and for my children to enter the workforce full-time rather than have to commit so much time to the care of their sibling.

Another major concern is the lack of safety via the public scrutiny provided by volunteers in autism support units in some mainstream schools. (e.g. Sherwood Ridge PS, Kellyville) compared to other schools that allow community participation and social inclusion of children with autism in support units.

### **How my life could be changed by a NDIS:**

We could provide our son with the aids, services and choices he deserves and enable our family to live a more normal life. For example, I would be able to return to work rather than being a full-time carer because I know we would be able to afford good quality care and monitoring of carers from remote locations. This peace of mind of knowing our son and our other children's sibling safe and happy is priceless. In addition, our health would improve, our finances would improve and our family would be stronger and the Australian tax payer would also benefit.

## NATALIE HOOD

### **Biggest issues:**

Accessing resources and information due to limited resources and financial cost.

### **How my life could be changed by a NDIS:**

It would alleviate the extra stress involved in trying to find financial cost for everything that is needed, and give our daughter more opportunities to access services and resources which will be beneficial to her. We would also be able access more information services, such as seminars and conferences which would enable us to further assist our daughter.

## JODY HARTFIELD

### **Biggest issues:**

Our child has cerebral palsy and as such needs constant care and supervision. This means as a mother, child care is not a desirable option and as such I am unable to work. Respite is therefore an important concept to us as a family, however we have not found it easy to obtain. The stress this causes on the family is profound. The loss in financial earning ability is also an issue, added to the extra costs involved in raising a disabled child.

### **How my life could be changed by a NDIS:**

To be able to provide the treatment, therapy, equipment, respite etc needed for a disabled family member would go a great way towards reducing stress on the family as a whole.

## RODNEY CLARKE

I have just finished reading the National Disability Insurance Scheme paper which is to be submitted to the Australian Government in response to their request to develop a National Disability Strategy...

This paper takes a holistic approach to addressing the needs of people with a disability in Australia:

- Servicing the physical support needs of the person with a disability
- Reducing the severe stress and impact on the family unit that provides the care for the person with the disability.

As a parent of a 12 year old boy with cerebral palsy, my heart has butterflies and my head is reeling with excitement at the prospect of this paper being approved!

My wife and I have spoken at length on, 'our future'. It is a topic which yields much pain and yet is something that we cannot avoid. Our son is 12 now and even though we toilet him, feed him, dress him, clean him, transport him, we are coping ... just.

But what about us? We didn't ask to have a child with a disability.

As childhood sweethearts, when we fell in love and married, our future was filled with love and opportunity and yet now, still with love, we are walking a razor thin line of stress, hardship and a future of pain and uncertainty.

You don't have to go far to read many stories of hardship at each phase of our children's tortured lives, from the initial diagnosis, through their education years, teenager, early adult and adulthood. Each phase of their life bringing with it stress for the parents, financial hardship, the identification of solutions, delays in implementing solutions, working with government departments and volunteer bodies just to reach some degree of 'normality' for your family. It never stops – until now.

The NDIS solution will remove a huge amount of uncertainty surrounding the care and wellbeing of my son, which in turn will relieve stress on my wife and I.

With the simple peace of mind in knowing that my child's wellbeing will be catered for after my wife and I die, we can stop stressing about the future and starting caring for our family now.

Thank you for caring about us.