

THE WAY FORWARD

A New Disability Policy Framework for Australia

Report of the Disability Investment Group

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In particular, the Group would like to thank Ms Lee Emerson, who headed the DIG Secretariat and Ms Helen Hambling, who drafted *The Way Forward* on behalf of the DIG, for their assistance in developing a potential new blueprint for disability services in Australia.

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22 September 2009

The Hon Bill Shorten MP
Parliamentary Secretary for Disabilities & Children's Services and
Parliamentary Secretary for Victorian Bushfire Reconstruction
House of Representatives
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Dear Parliamentary Secretary,

DISABILITY INVESTMENT GROUP

On behalf of the Disability Investment Group (DIG) it is my pleasure to present you with our report, "The Way Forward – A New Disability Policy Framework For Australia".

When the DIG was initially formed you challenged us to think creatively about how to inject additional resources into the historically underfunded disability sector. In the course of lengthy discussions amongst ourselves, with people with disabilities, with family members and other carers who support people with disabilities, and with experts in the field, it became apparent that individual measures such as tax concessions to encourage additional private expenditure would, of themselves, be as useless as throwing a cup of water on a raging fire.

Despite Governments spending around \$20 billion annually on the disability welfare system (with billions more spent on other services in relation to people with disabilities) there remains a large, and rapidly growing, unmet need for care and support. This is despite an estimated army of 2.5 million family members and other carers providing unpaid care and support.

The lack of proper planning and integrated service delivery is a national disgrace and with increasing demand for, and increasing cost of, these services (formal costs of the disability system are projected to rise in real terms by 5%–10% pa in coming years) the situation for people with disabilities and their carers will undoubtedly worsen so long as the current arrangements remain in place.

Accordingly DIG believes fundamental change is required.

It is the strong view of DIG that structural reform is required in the framework governing disability policy in Australia. If this transformational shift occurs as suggested by DIG then the system would move from one based on short-term and often ad hoc resource allocation—with all of the inefficiencies and inequities involved—to a rational system where need, rather than happenstance, determines resource allocation. A whole new world of opportunities would be opened up for people with disabilities, and the families and other carers who support them.

We believe that a National Disability Insurance Scheme (NDIS) is required to create the transformational shift to move care and support for people with disabilities out of the dark ages and into the 21st Century. We believe that further analysis is required but on the basis of the substantial work in this report we are confident that the NDIS represents the way forward.

The new order would replace the welfare model of disability services with a 3 pillar policy to support people with disabilities. The 3 pillars are:

- (i) a comprehensive NDIS to deliver care and support for life for people with severe and profound disability using an individualised and lifelong approach; including reform of state-based insurance schemes to include all traumatically injured people. This would be the bedrock of the whole system;
- (ii) a strong income support system that facilitates people with disabilities who cannot support themselves through work, to live in dignity; and
- (iii) a range of measures to facilitate increased private expenditure.

Our central recommendation is that the Australian Government, in consultation with States and Territories, immediately commissions a comprehensive feasibility study into a National Disability Insurance Scheme (NDIS).

I wish to acknowledge and thank the members of the DIG who all spent a massive amount of time on this task – Bruce Bonyhady; Allan Fels; Bill Moss; Mary Ann O’Loughlin (who stepped down from DIG in October 2008); Kathy Townsend; and John Walsh.

I particularly wish to recognise Bruce Bonyhady, who has made a massive contribution to this report. I also wish to thank the staff of FaHCSIA who have assisted DIG including Lee Emerson, and especially Helen Hambling who has done a wonderful job in drafting the report.

The DIG commends the report to the Government and in particular the central recommendation of the immediate commissioning of a comprehensive feasibility study into a National Disability Insurance Scheme (NDIS). An NDIS represents an exciting way forward for Australians with a disability and for their families and carers.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'IAN SILK', written in a cursive style.

IAN SILK
Chairperson

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Executive Summary

In April 2008, the Parliamentary Secretary for Disabilities and Children's Services, the Hon Bill Shorten MP, established the Disability Investment Group (DIG). The Group's role was to explore innovative funding ideas from the private sector that will help people with disability and their families access greater support and plan for the future. The Group's Terms of Reference and Membership are at Appendix A.

The DIG's focus on the idea of investment rather than on the more traditional notion of welfare has generated some practical ideas for policy direction and development—*The Way Forward*—that could transform the experience of disability in Australia.

While the DIG was conducting its review, the Australian Government undertook a number of initiatives to bolster the current systems for supporting Australians with disability. The measures include signing the *UN Convention on the Rights of Persons with Disabilities*, increasing the Disability Support Pension and Carer Payment in the 2009–10 Budget and allocating increased funding under the National Disability Agreement over the next five years.

More recently, the Consultation Report from the National Disability Strategy—*SHUT OUT*—which was prepared by the National People with Disabilities and Carer Council, was released by the Commonwealth Government. Its conclusions are based on 750 submissions and the feedback from the 2,500 people who attended the public consultations, and highlights that many people with disability feel excluded from an ordinary life.

Its conclusions are consistent with the findings of the DIG that current policy settings of all governments are leaving multiple barriers for too many people with disability and their families, notwithstanding recent increase in government funding. These barriers are less to do with particular impairments and more to do with the lack of guaranteed access to customised plans of timely support and development.

DIG members consulted with a range of individuals and organisations who offered ideas to create incentives for private investment in disability. The strong theme of these discussions was the vital need to introduce certainty and confidence into the lives of people with disability and their families. The ability to plan for a life and a future underpins the aspirations of all Australians.

The DIG's principal recommendation is that the Commonwealth Government, in consultation with States and Territories, should immediately commission a comprehensive feasibility study on a National Disability Insurance Scheme (NDIS). The DIG believes that further analysis is necessary because, while a NDIS would be transformational, some of the transition and other issues associated with its introduction would be complex.

The scheme would revolutionise support for people with disability. It would be person-centred, have a genuine whole-of-life focus and maximise independence and participation. It could transform a well-meaning but fragmented welfare model into an innovative, social insurance scheme achieving better outcomes through need management and service efficiency.

The feasibility study should examine the longer-term cost implications, noting that within a generation, the costs are likely to stabilise at less than projected costs of the current system.

There is a compelling case to not only achieve long overdue equity for people with disability, but also to provide security in the event of severe or profound disability for all Australians and establish long-term sustainability of the disability support system.

Drawbacks of the current system

Australia has a robust social security system which entitles all citizens to health services and income support based on individual needs and circumstances. However, while Australians with disability are entitled to these universal services, there is no equivalent entitlement to disability care and support services.

The Australian system of formal support is failing many people with disability, their families and carers. There are high levels of unmet need for disability services impacting heavily on people with disability but also on their families and informal carers. Families are usually more than willing to care for family members with disability when they are able to do so. However, without support and assistance families can 'burn out' with higher ultimate costs to governments.

While all levels of government have increased funding for disability services in recent years, no government has committed to meeting all the essential needs of people with disability. Governments fund a range of services, but people with disability and their families have no certainty and no guaranteed access to a system of core support. The reliance on informal carers has enabled the effective rationing of resources to those in or on the verge of crisis.

A major drawback of the current disability services system is that the client is not at its centre. While moves to more individualised packages of care are welcome, there is little opportunity for life course planning for individuals, which involves their families, helps them meet their aspirations, and prepares them for key transitions.

The current system is under considerable stress and marginal change or add-on services will only lock in models that will continue to fail to meet the needs of people with disability, their families and carers. Traditional program responses can do little to ease the pressure of rising costs of services to government and they do not provide value for money in improved outcomes for clients.

A more robust governance structure and evidence base is needed to help guide effective and integrated planning and service delivery, and to re-evaluate outcomes. Currently, there is limited and uneven data collection and monitoring capacity.

Emerging pressures

Looking ahead, Australia's ageing population will increasingly stretch the existing system, given the strong correlation between age and disability. This means that over the next decades there will be a steady increase in the number of people with a severe or profound disability. For the next 70 years, the projected growth rate in the population with severe and profound disability is between two and three times the population growth rate as a whole.

While the number of people with disability continues to grow, the availability of informal care is contracting. Fewer people take on informal caring roles because of a range of factors including increasing workforce participation by women and decreasing core family size. The impact of these trends on the disability services system will be significant. Because non-paid care provides for more support than paid care, a 10 per cent reduction in providing informal care translates into a 40 per cent increase in the need for funded services.¹ Already we are seeing that ageing carers find it difficult to continue to care and many now need assistance themselves.

A transformational shift

The DIG has concluded that a transformational shift in policy approach and service delivery is needed. It is now time to rethink and restructure the basis of disability policy in Australia. The group recommends a three pillar policy to support people with disability, similar to the structure for retirement incomes.

The proposed new policy framework focuses on government and private investment to assist people with disability to manage their own lives and maximise their independence and contribution to the community.

The welfare model of disability services needs to be replaced with a new three pillar policy to support people with disability. The three pillars are:

- a **new and comprehensive National Disability Insurance Scheme** to deliver care and support for life for people with severe and profound disability using an individualised and lifetime approach, including reform of state/territory-based insurance schemes to include all traumatically injured people (*see part 3*);
- a **strong income support system** that facilitates people with disability who cannot support themselves through work, to live in dignity (*see part 4*); and
- a **range of measures to enable increased private contributions** (*see part 5*).

The key to this transformational shift would be the introduction of a **National Disability Insurance Scheme** which would provide people with severe or profound disability with an individualised and lifetime approach to care and support.

The scheme would replace the current arrangements for funding disability services and would work in a similar way as the no-fault injury insurance schemes that currently operate in some States and Territories. Coordinated services would provide care and support including aids, equipment, transport, respite, accommodation support and a range of community and day programs.

A proposed model of the scheme is summarised on pages 6–8 and outlined in more detail in Part 3.

With full actuarial accounting of the lifetime costs for each individual, a NDIS would mean more effective and timely investments and interventions. The scheme would also help individuals to maximise their potential and provide opportunities to reduce long-term care and support costs.

The *Australia 2020 Summit* early in 2008 recommended such a scheme. Three other recent reports have also advocated further investigation of schemes along the lines of a NDIS: the Pension Review Report; the House of Representatives Standing Committee on Family, Community, Housing and Youth Report: *Who Cares? – Report on the inquiry into better support for carers*; and the National Disability Strategy Consultation Report *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*.

Such a scheme is not beyond Australia's capacity to deliver. In fact the DIG believes that ultimately a NDIS would be a net saving on government expenditure through a more effective service system and better employment, health and social outcomes for people with disability.

Increased expenditure would be necessary to address currently unmet need for care and support, estimated at \$0.97 billion in the first year and \$2.04 billion in the second year. However, because of the more active management and support model, sizeable offsets will be available from Disability Support Pension (DSP), Carer Payment, health, aged care and other social programs.

Additional offsets are also likely, as the introduction of a core NDIS would also enable a range of innovative private investment opportunities to emerge. With a certain and reliable stream of ongoing essential care and support, individuals and families would be encouraged to make additional private provision for the future in areas such as housing, in the same way as compulsory superannuation has encouraged additional private contributions to retirement savings.

As the second and third pillars (income support and measures to enable increased private contributions) are part of the tax transfer system, they should be considered in the context of the current Review into Australia's Future Tax System.

A NDIS should be complemented by nationally consistent state-based insurance schemes covering motor accident, workers' compensation, public liability (general injuries) and treatment injury. To ensure a comprehensive and equitable national approach, the Commonwealth, States and Territories should work together to consider how the various insurance schemes that provide lifetime care and support for traumatically injured Australians can become no-fault and nationally consistent with the proposed new scheme.

Other improvements to services and support

Three more DIG recommendations are designed to help improve other aspects of services and support for people with disability, their families and carers. These are:

- **better employment opportunities** for people with disability—mainly through changes to the Disability Employment Services;
- **meeting the housing needs** of people with disability by adjusting the new National Rental Affordability Scheme (NRAS), to provide an extra payment—NRAS Plus, and **strengthening the regulations** for accessible and adaptable housing standards—to provide affordable and accessible housing for people with disability; and
- **investing in a centre of excellence for disability research**—to build the evidence base, with more coordinated and reliable data collection.

The National Disability Insurance Scheme (NDIS) – A Possible Model

- A NDIS would provide a lifetime approach to care and support for people with disability and would replace the current arrangements for funding specialist disability services.
- A social insurance model is proposed. It would assess the risk of disability in the general population; calculate the costs of meeting the essential lifetime needs arising out of these disabilities; and estimate the premium or contribution required from taxpayers to meet these needs.
- Instead of funding capped programs and services for people with disability to find and access, the scheme would fund on the basis of each individual's needs which would in turn drive the development of necessary care and support services.
- The costs of a NDIS could be funded from general revenue or through a Medicare-like levy.
- Implementation should be staged over 7 to 10 years to enable new service infrastructure and workforce to develop, and to balance the constraints of the medium-term fiscal outlook against intergenerational trends.

Who would be eligible?

- People with a severe or profound disability acquired before 65 years of age would be eligible for life. People with a severe or profound disability are those who always or sometimes need help with a core activity or task.
- Carers would also be recognised and supported in their roles and opportunities to combine caring and work would be encouraged.
- People who are covered by state/territory-based accident compensation schemes would continue to be covered by them, however, the interaction of these schemes should be further investigated.
- The scheme would cover the existing eligible population under age 65 years when the scheme starts as well as people who become eligible in the future.

What services and benefits would people receive?

- Coordinated services based on need would provide care and support including respite, aids, equipment, transport, home modifications and a range of community and day programs.
- Other support funded outside the scheme such as income support, housing and employment services would be integrated to provide support and opportunities for people with disability as part of a holistic approach.
- There would be an emphasis on early intervention and access to education and training to maximise long-term independence and potential.

How would the Scheme be governed?

- A NDIS would operate under a new National Disability Commission, possibly a statutory authority, with a formal and independent governance model comprising a prudential board of directors to oversee the operation of the scheme and an advisory council of stakeholders to provide policy advice on the appropriateness and quality of the benefits.
- Insurance principles would underpin the new arrangements. In particular surplus premiums would need to be invested to maximise long-term returns, while active claims management, through comprehensive data analysis, research and provider monitoring, would lead to significant improvements in efficiency and effectiveness.

What are the benefits?

- People with disability and their families would have certainty and clarity about options from the point of determination of a disability.
- Eligible people would be entitled to services determined on an individualised plan and needs basis, giving them access to an appropriate whole-of-life suite of services and support.
- Families would have more choices about the combination of work and informal care for family members at various life stages, as in other families.
- The proposed scheme addresses the current unmet and under-met need for care and support and the unsustainable reliance on carers.
- For the first time there would be clear incentives in the service system to invest in timely interventions that promote independence and produce long-term benefits.
- The introduction of a NDIS would provide a sound platform of lifetime support to enable a range of innovative private contributions from individuals and families.

Principal Recommendation

Recommendation 1

DIG recommends that the Commonwealth Government, in consultation with States and Territories, immediately commission a comprehensive feasibility study into a National Disability Insurance Scheme (NDIS).

The scheme would:

- *be designed to meet existing, unmet and future needs of people with severe or profound disability for life, where disability is acquired before age 65;*
- *replace and enhance current arrangements for funding and providing disability services;*
- *be based on a social insurance model and fund a basic level of personal care and support for life;*
- *be administered by a new statutory authority with a robust prudential governance structure;*
- *be funded from general revenue or a Medicare-like levy, in recognition of the shared public risk of disability; and*
- *have a staged implementation over 7 to 10 years to allow for the development of the necessary infrastructure and workforce.*

The feasibility study should also consider:

- *how State and Territory accident insurance schemes should interact with the proposed national scheme and move to providing nationally-consistent, no-fault insurance for traumatically injured people; and*
- *the potential to enhance additional private provision for people with disability by making a NDIS the centrepiece of a new three pillar disability policy framework.*

The DIG also recommends that any work commissioned on the feasibility of Medicare Select should align with work on the feasibility study of a NDIS.

Proposed Terms of Reference for a feasibility study are at Appendix B.

Summary of Other Recommendations

Recommendation 2

DIG recommends that the feasibility study into a National Disability Insurance Scheme includes further examination of the potential for any of the following measures to enhance additional private provision for people with disability.

- *Action on the recommendations of the Senate Standing Committee on Community Affairs in its report on Special Disability Trusts, Building trust: Supporting families through Disability Trusts, October 2008.*
- *Setting up a savings plan with incentives for family members to save for the short- to medium-term financial needs of a family member with disability.*
- *Removing taxes on essential goods and services required by people with disability, their families and carers.*
- *Introducing a Disability Support Tax Rebate into Australia's tax system to recognise the work-related costs of people with disability, their families and carers.*
- *Development of private housing and services models that could complement a NDIS.*

This would require consultation with other parts of government, including importantly, the Review into Australia's Future Tax System.

Recommendation 3

DIG recommends that regulations for accessible and adaptable housing standards be strengthened to facilitate ageing in place; and as a first step, a set of no-cost and low-cost requirements be mandatory for all new residential buildings.

Recommendation 4

DIG recommends that the National Rental Affordability Scheme (NRAS) be amended to better meet the needs of people with disability by:

- *increasing the payment made in relation to housing for people with disability to recognise the higher costs of providing and servicing their housing (NRAS Plus); and*
- *setting minimum adaptability and accessibility standards at least equal to the no-cost or low-cost standards in Recommendation 3.*

Recommendation 5

DIG recommends a change of focus for Disability Employment Services (formerly Disability Employment Network) to direct candidates with disability into the mainstream employment market, rather than act as employment agencies in their own right; and to ensure that services are appropriately targeted and delivered in a way that the private sector will access them.

DIG also recommends that access to funded services in the Disability Employment Services be available to people in Australian Disability Enterprises who want to take up employment in the open labour market.

Recommendation 6

DIG recommends that the Commonwealth and State and Territory Governments allocate \$30 million per annum under the new National Disability Agreement to fund a National Disability Research Institute as a centre of excellence to lead and promote disability research in Australia. The National Disability Insurance Scheme would be expected to maintain and expand this research.

Section I: Disability in Australia

Part 1: Experience of Disability in Australia

People with disability

One in five people in Australia (3,958,300 or 20 per cent) reported disability in 2003. A further 4,149,000 (or 21 per cent) had a long-term health condition that did not restrict their everyday activities. Approximately 595,000 people (3.0 per cent) reported a profound disability, and a further 650,000 people (3.3 per cent) reported having a severe disability.²

About 1 in 12 children aged up to 14 years, had a disability (8.3 per cent of all children), and half of these had a severe or profound limitation.

The number of people aged 0–64 years with severe or profound core activity limitations is projected to grow substantially between 2006 and 2010. The Australian Institute of Health and Welfare estimates an increase of 4.8 per cent to 752,100 people.³ The Institute also suggests that increases over recent decades in the prevalence of some long-term health conditions, particularly related to disability, may result in further increases in the size of this population.⁴

Generally, the prevalence of severe and profound disability increases with age, and is of particular significance for an ageing population. Over the next 40 years, a steady increase in the number of people with severe or profound disability will continue (projected to grow from 1.4 million to 2.9 million).⁵ Over the next 70 years, the rate of growth in the severe and profound population is between two and three times the rate of growth of the population as a whole.

Since the 1980s, policy trends have emphasised de-institutionalisation of health and welfare services. Between 1981 and 2003, there was a strong trend towards people aged less than 65 years with severe or profound limitations living in the community.

While the total number of people aged 5–64 years with severe or profound limitations rose by 137 per cent, or 371,000 people, the number living in cared accommodation fell by 40 per cent. The type of living arrangement with the largest increase over the period was people with severe or profound limitations living with family—an additional 318,000 people aged 5–64 years lived with family in 2003 compared with 1981. As a percentage of people aged 5–64 years with severe or profound limitations 1 in 40 lived in cared accommodation in 2003, compared with almost 1 in 10 in 1981.⁶

Carers

In 2003, approximately 2.5 million people reported providing informal care to a person because of disability or old age. Of these 2.5 million people, approximately 20 per cent (or 474,600 people), reported being the primary carer of a person with disability. Of these carers, 187,500 (40 per cent) had disability themselves.⁷ Using assumptions on average hours of care per week for primary and non-primary carers, there were approximately 643,000 full-time equivalent informal carers in Australia in 2003, providing an estimated 24.4 million hours of care per week.⁸

Primary carers are likely to be in the poorest two-fifths of all households and 55 per cent receive income support as their main source of cash income. Most primary carers (71 per cent) are women.

Nearly two-thirds of primary carers were not employed (295,000) and almost one-third had left work just prior to taking on the caring role. Just over half of primary carers in this situation had left work specifically to start or increase care.

Of all primary carers who had left work to start or increase care, 38 per cent had done so because alternative care was not available or too expensive, or because they were unable to change their working arrangements. However, the remainder had done so due to other reasons such as emotional obligations or because they preferred to care full-time (62 per cent). Around 57 per cent of male primary carers who had left work to take on the caring role had done so because alternative care was not available or too expensive, or because they were unable to change their working arrangements.

It is a common scenario in Australia that a parent then spouse or sibling then child will support a person with disability over their lifetime. It appears that in many situations the parent will be the carer until it is no longer possible for them to care for their son or daughter.

Recent research by the Australian Institute of Family Studies found that carers and families of people with disability experience high rates of mental health problems, poor physical health, employment restrictions, financial hardship and relationship breakdown.⁹

The ratio of informal carers to the number of people with disability is projected to fall.¹⁰ This is attributed to Australia's low fertility rate over recent decades, higher rates of family breakdown, and increasing participation of women in the workforce.

Part 2: Need for Change

The Australian system of formal support is currently failing many people with disability, their families and carers. In future, the system will be under greater pressure because of demographic changes that reflect the ageing population and the shift towards more single-person households.

In July 2008, the Australian Government signed the *United Nations Convention on the Rights of Persons with Disabilities*. The parties to the Convention:

...recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability.¹¹

To lift Australia's record in assisting its citizens with disability to live the lives to which they aspire, the current disability system needs immediate and significant reform. This must be on the scale of the Medicare reforms or the introduction of compulsory superannuation.

Greater stress in the future

With increasing numbers of people with disability, decreasing availability of informal carers, and an ageing population, there will be even greater stress in future on the fragmented service system and a growing unfunded liability for families and governments.

Recent trends indicate growth in demand for specialist disability services of 7.5 per cent per annum in real terms.¹² Government spending on disability services has not kept pace with this. Improving system efficiency and effectiveness is critical in managing the future costs of disability from an intergenerational perspective.

The reforms under the new National Disability Agreement to build new disability service systems within each State and Territory will undoubtedly improve the current disability system, which has been 'hamstrung for years by buck-passing and a culture of reactive crisis management, to the detriment of those it is meant to support'.¹³

Under the Agreement, the Commonwealth, State and Territory Governments' commitment to person-centred approaches, single access points, quality assurance systems and benchmarking is welcome and an acknowledgement of the need for change. However, the DIG believes that more fundamental reform is needed that builds on the practical experience of the injury compensation and no-fault motor accident schemes operating in some Australian states, New Zealand and other countries.

Support over the life course

Internationally and across Australia interest in new approaches that have a life course perspective is growing—an approach which recognises the way lives develop and change, rather than the static point-in-time approach of our current welfare system.

Fundamentally re-engineering the way public and private resources are invested in disability would allow people with disability, their families and carers to plan with more certainty across the life course, and to contribute more to Australian community life. For governments, a new and sustainable funding system, with a rigorous governance framework, would ensure an unprecedented level of prudential and social planning.

The recent National Disability Strategy Consultation Report *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*¹⁴ prepared by the National People with Disabilities and Carer Council cited a significant number of submissions arguing for fundamental reform to the disability services and support system. While details varied, these submissions argued that a lifetime care and support scheme such as the proposed NDIS would remove existing inequities and provide the resources needed to ensure that people with disability are able to reach their potential and live as independently as possible.

Committing to long-term investment

The DIG proposes a three pillar policy based around long-term investment to support people with disability. At the heart of the proposed new system is the goal of realising personal potential through a new National Disability Insurance Scheme.

By introducing a new approach government investments would no longer focus on just the care and support that people with disability need. The focus would shift to assisting people with disability to manage their own lives, to maximise their independence and contribute more to the community.

Income support and the new insurance arrangements would operate side by side, supplemented by improved arrangements for families to make planned complementary provisions for the future for family members with disability.

Improved employment and social housing services would maximise the potential of these long-term investments.

Section II: A New Approach

Part 3: Establishing A New National Disability Insurance Scheme

Recommendation 1

DIG recommends that the Commonwealth Government, in consultation with States and Territories, immediately commissions a comprehensive feasibility study into a National Disability Insurance Scheme.

The scheme would:

- *be designed to meet existing, unmet and future needs of people with severe or profound disability for life, where disability is acquired before age 65;*
- *replace and enhance existing arrangements for funding and providing disability services;*
- *be based on a social insurance model and fund a basic level of personal care and support for life;*
- *be administered by a new statutory authority with a robust prudential governance structure;*
- *be funded from general revenue or a Medicare-like levy, in recognition of the shared public risk of disability; and*
- *have a staged implementation over 7 to 10 years to allow the development of new infrastructure and workforce.*

The feasibility study should also consider:

- *how State and Territory accident insurance schemes should interact with the proposed national scheme and move to providing nationally-consistent, no-fault insurance for traumatically injured Australians; and*
- *the potential to enhance additional private provision for people with disability through further consideration of measures such as:*
 - *reformed Special Disability Trusts;*
 - *models of private and social investment in housing for people with disability such as the Hope Australia Urban Village and Forester's Community Finance;*
 - *removal of taxes on essential goods and services required by people with disability, their families and carers; and*
 - *introduction of a Disability Support Tax Rebate to recognise the work-related costs of people with disability and carers.*

The DIG also recommends that any work commissioned on the feasibility of Medicare Select should align with work on the feasibility study of a NDIS.

Proposed Terms of Reference for a feasibility study are at Appendix B.

Key DIG findings

Australian governments commit approximately \$20 billion per annum in total to the disability welfare system, of which about \$8 billion is on payments to community care and support providers. In addition, nearly \$3 billion is paid to family and other informal carers. The bulk of the remainder (about \$9 billion) is paid in income support for about 700,000 Australians with a work incapacity through the DSP.¹⁵

Eligibility, assessment and access to disability services vary across States, Territories and regions, and across individual services. Capacity constraints can mean long waiting lists and variable costs for families. As well, valuable resources are wasted on managing demand and rationing services, rather than on meeting the needs of people with disability and their families.

From an individual's or family's perspective services can be highly uncertain, fragmented and disconnected. Many families say that 'it is like finding a way through a maze'.¹⁶

A comprehensive system to support people with disability has to provide individualised lifetime care and support. The DIG recommends a new social insurance approach. A NDIS would differ from a welfare safety net approach in the way it meets the needs of claimants across the life course, prices and generates the funds for the scheme, and in its management and governance.

Addressing current policy shortcomings

Historically in Australia, governments have allocated a share of consolidated revenue for people with disability as a partial response to expressed demand. Access to the disability services under the National Disability Agreement¹⁷ or the Home and Community Care program is not an entitlement. Because funds are capped and allocated through particular programs in particular areas, services are rationed. Government funding supports a range of community-based services on the basis that people with disability will find them and that the services will be able to go some way to meeting their needs.

However, despite significant growth in funding by all levels of government in recent years, there remains considerable unmet need for services which is largely met by families and informal carers—that is, until a crisis such as the death or illness of a carer.

Alternatively people with disability simply go without services, aids and equipment or other assistance that would improve the quality and productivity of their lives. In many cases the lack of essential services and equipment leads to increased disability, increased dependence and increased long-term costs.

One of the messages that emerged from the DIG consultations was that families perceived that the shortfall in funding meant that State and Territory Governments focus on providing disability services for people with complex needs and challenging behaviours, and that individuals with less severe, though often still serious disability, have to wait longer for support.

While some States and Territories have trialled individualised care and service packages, the current disability services system does not have the client at its centre and, at best, services are based on the point-in-time needs of their clients.

Current services are generally not well placed to invest in early interventions that could improve personal outcomes and lower future liabilities. There is little opportunity for planning over the life course with individuals and their families to help prepare for key transitions and risks before they happen. At a systemic level, there is simply not the robust data or monitoring capacity across the current fragmented system to enable effective integrated planning and continuous re-evaluation of outcomes.

National Disability Agreement

The Australian governments have recognised some of these shortcomings. In July 2008, Community and Disability Services Ministers acknowledged that 'people with disability, their families and carers are often faced with a fragmented service system lacking in early intervention and often driven by crisis'.¹⁸

The current approach to improving disability services has been to increase funding under the National Disability Agreement and to gain commitment from States and Territories to improve the existing system.

The Commonwealth is providing approximately \$5 billion in funding over five years to the States and Territories to provide for more services and to achieve reform of the disability service system over the life of the new Agreement. Under the new Agreement announced at the Council of Australian Governments in November 2008, States and Territories have committed to build 'end to end disability services systems within each state'.¹⁹ The key elements of the reform of the disability service system are:

- early intervention and planning to ensure that clients receive the most appropriate and timely support;
- improved measurement of unmet demand for disability services;
- population benchmarking of disability services;
- a national workforce strategy to address attraction and retention of the disability services workforce;
- a national quality assurance system for disability services; and
- national harmonisation of aids and equipment.

The DIG's view is that these are important initiatives moving in the right direction but on their own will not deliver the individual and life focus that is required to enable people with disability and their families to maximise their potential.

Level of unmet need

Because of limited reliable data, it is very difficult to determine the level of current unmet need for services for people with disability. A 2005 Australian Institute of Health and Welfare analysis²⁰ of Commonwealth State Territory Disability Agreement funded services, showed a high level of unmet need. Noting that its estimate of community access to services was conservative, the analysis found:

- unmet demand for accommodation and respite services—23,800 people; and
- unmet demand for community access services—3,700 people.

Since then, unmet demand for specialist disability services has risen, with recent trends indicating a 7.5 per cent growth each year in real terms. Government spending on disability services has not kept pace with this.

In work undertaken for the NSW Government in 2004, PricewaterhouseCoopers (PwC) analysed potential unmet need by considering the proportion of care needed over time if current service levels remain the same. PwC grouped people with severe and profound disability into relative support needs and estimated the difference between hours needed and hours provided.

PwC estimated that unmet need for people requiring constant support would grow from 1 per cent of what they require in 2004 to 49 per cent by 2031. For those requiring regular support, unmet need will grow from 25 per cent in 2004 to a projected 48 per cent in 2031; and for those requiring lower support, unmet need will grow from 77 per cent in 2004 to a projected 90 per cent by 2031.

Without sufficient formal care and support, people with disability will continue to rely heavily on their families, and the current system will continue to even more tightly ration resources specifically to those in or on the verge of crisis. This will lead to increasing 'burn out' of carers and families with higher ultimate costs for governments. Many carers are too exhausted to work in paid employment or will themselves become disabled.

Incentives to invest

The proposed NDIS would create a compelling incentive to invest in individual capacity. For the first time, the scheme would establish a direct relationship between improved capacity and moderating future costs.

Timely interventions and treatments, appropriate aids and equipment, and training and development that improve functioning become sensible investments rather than welfare handouts. The scheme would lead to more positive results for a person's wellbeing as well as being fiscally responsible.

A NDIS could also be structured to create incentives for families to invest or co-invest in services and support and thereby further contribute to lower long-term costs to government.

Basis for the proposed model

PwC worked with the DIG to consider the costs, benefits and governance of a National Disability Insurance Scheme. The Executive Summary of the PwC Report is at Appendix C.

This work assisted the DIG to develop the model that is now recommended to the Australian Government as a starting point of what should be a more detailed feasibility study. Clearly there is a wide range of issues and variables to be considered in the design of such a scheme. For the purposes of this exercise the DIG assumed a number of parameters to test the implications of a new insurance approach.

There will be different views about the elements of the proposed model and therefore these should be considered in more detail in the proposed next phase—the feasibility study. However, the DIG believes that the social insurance approach reflected in its recommended model offers a practical and sustainable option for dramatically reforming the system of care and support for people with disability in Australia. Adopting this approach would signal a commitment to meeting the essential needs of people with disability.

The Australian Government Actuary (AGA) was asked to assess the reasonableness of the approach taken by PwC to cost the scheme. In summary, the AGA concluded that he was satisfied that PwC's costings are consistent with their underlying population estimates and projections, the observed aggregate severity distributions and the assumed dollar cost distributions. The AGA noted the sensitivity of the population estimates to the assumptions around eligibility and exit rates from the scheme and consequently, the actual population could differ significantly from the PwC estimates. This would flow through to the costs of the NDIS. Nonetheless he concluded that the approach taken by PwC was reasonable in the circumstances.

The proposed NDIS would provide clients with an individualised and lifetime approach to care and support. The scheme would treat people equally on the basis of need, not on the basis of the cause of the disability, the State and Territory in which they live, or what services happen to be available. The scheme would work in a way similar to the no-fault injury insurance schemes that currently operate in some States and Territories.

Scheme coverage

The scheme would cover people with a severe or profound disability (that is, people who always or sometimes need help with a core activity or task) with onset before 65 years of age. It would cover care and support and related services on a needs basis for this population, for life.

The 2009 prevalence (including one year of new incidence) of this population is about 600,000, with condition groupings as follows:

- sensory conditions (12,000);
- injury (15,000);
- nervous system disorders (41,000);
- congenital anomalies and intellectual disability (82,000);
- mental illness (206,000); and
- physical conditions (223,000).²¹

Further work is needed to consider the extent to which all of these conditions (particularly some of the physical conditions where the care required is very illness-related) are appropriately funded through a disability insurance system rather than through the health system. The physical group is largely made up of people with care needs stemming from cancer, musculoskeletal diseases, diabetes and stroke. The DIG has included these conditions in the proposed model, however, if this group was excluded the scope and cost of the scheme would be significantly reduced.

Similarly the age cut-off for entry into the scheme could be considered in this context. On balance, the DIG takes the view that people who acquire disability over the age of 65 years are better treated in the aged care and health systems.

Considered by severity of support need, the distribution of the population includes:

- constant support need (40,000);
- frequent support needs (104,000);
- regular support needs (32,000);
- Grade B lower support need (86,000); and
- Grade C lower support need (316,000).²²

New National Disability Insurance Scheme

Coverage

- People with severe and profound disability, acquired before the age of 65 years, would be eligible for life.
- The scheme would cover the existing eligible population at start-up as well as new incidence.
- An entry assessment tool would be developed based on functional requirement rather than cause of impairment or medical diagnosis, replacing the multitude of existing assessment instruments.
- Coordinated services would provide care and support including respite, accommodation support, aids, equipment, transport and a range of community and day programs.
- Income support, housing and employment services would remain separately funded from the scheme, but should be integrated to provide support and opportunities for people with disability as part of a holistic approach.

Income support for people with disability is provided through the DSP. While the DSP has recently been reviewed as part of the Pension Review and, like other income support entitlements, is funded from general revenues, it may be preferable to explicitly include contingencies for future income support for people with disability within the scheme.

This approach would strengthen the incentives to invest in people with disability to fulfil their potential to participate and contribute to the community in the same way as other Australians. The implications of this approach should be considered further in the feasibility study as it could have significant long-term benefits in terms of lower costs as well as better outcomes.

A social insurance approach

A NDIS would replace the current arrangements for funding disability services and would work in a similar way to the no-fault injury insurance schemes that currently operate in some states. The scheme would operate as a social insurance scheme reflecting the shared risk of disability across the population.

Under a social insurance approach, the risk of disability and the costs of meeting lifetime needs are the starting point. The necessary funding is then actuarially estimated after considering the expected claims, expenses and the cost of capital, while also considering the desired outcomes for scheme participants across their lives.

Phased implementation over 7 to 10 years would enable the necessary growth in service infrastructure and workforce. Investment would rise incrementally over time. Funding for the scheme could come from general revenue or a Medicare-like levy.

For the first time an integrated system of funding, purchasing and delivering disability services would be available in Australia. The proposed scheme would help to address unmet and under-met need for care and support and the unsustainable reliance on carers. At the same time, the scheme would ensure a viable system and engage in partnerships between funded support, informal support and community-based activity and infrastructure.

The DIG notes that the recently released final report of the National Health and Hospitals Reform Commission (NHHRC) *A Healthier Future for all Australians* proposes the establishment of health and hospital plans under a scheme entitled Medicare Select.²³ These plans would cover the whole of a person's care through life. The NHHRC suggests that this would provide strong incentives to focus on prevention and better management of chronic diseases through early intervention, service integration and coordination and also drive innovation. The NHHRC notes the possibility of extending coverage to disability services.

The DIG notes that any work commissioned on the feasibility of Medicare Select should align with work on the feasibility of a NDIS.

The introduction of a core NDIS could also enable a range of innovative private investment opportunities to emerge. With a certain and reliable stream of ongoing essential care and support, individuals and families would be encouraged to make additional private provision for the future in areas such as housing, in the same way as compulsory superannuation has encouraged more private contributions to retirement savings.

Implementation

- Phasing the implementation and investment in the scheme over 7 to 10 years would enable the necessary growth in service infrastructure and workforce. It would also recognise that many families will want to plan and transition gradually from their current informal care arrangements to more formal support structures.
- The DIG proposes that the additional cost of the scheme be funded from general revenue or by a Medicare-type levy reflecting the shared risk of disability amongst the population.

Whole-of-life response

Under the scheme, coordinated services would provide care and support including aids, equipment, transport, respite, accommodation support, and a range of community and day programs.

People with disability and their families would have certainty and clarity about options from the point of diagnosis of a disability. Each person would be entitled to an appropriate whole-of-life suite of services that would facilitate independence and maximise potential. As in other families, this is still likely to be a mixture of formal and informal care, as individuals and families make decisions about appropriate arrangements at various stages of life.

Management, governance and risks

To be sustainable an insurance scheme must be well-governed and managed. The DIG proposes that a new statutory authority be established to govern the NDIS.

The scheme would also require disciplined monitoring and evaluation across a number of dimensions of each client's life plan such as health outcomes, work outcomes and service use.

The proposed model faces two key risks.

- The scheme could become financially non-viable. Australia limits the current disability system by rationing expenditure through fixed budgets and some indexation. These limits have resulted in the current levels of unmet need. In the proposed scheme, a strong prudentially-focussed and commercially oriented board of directors would deal with this risk by managing downward pressure on costs.
- Stakeholder support for the new scheme may decline because of dissatisfaction with the quality of services and poor outcomes for clients. A 'demand-push' by beneficiaries and/or their carers and advocates for more benefits would put upward pressure on costs and would need to be managed by clear engagement with stakeholders (beneficiaries and carers) and their representatives. An advisory council including representatives of beneficiaries, carers, service providers and governments is proposed to provide advice on quality and appropriateness of services.

Drawing on the experience of accident compensation schemes, these two opposing pressures can be harnessed through good governance to achieve a balance between available benefits and affordable levies.

Parameters

The costs of a NDIS will depend on ultimate decisions about the parameters and operation of the scheme such as coverage, level of service provided and funding arrangements (pay-as-you-go, partial or full funding), and will need to be calculated in the context of a detailed feasibility study.

To provide an indicative gross cost of the DIG model, PwC used a range of assumptions around service models and triangulations of data sources, noting that none were specifically designed for this purpose.

The assumed service model for a NDIS recognises current unmet and under-met need, and so seeks to address the current unsustainable reliance on informal carers, as well as future needs. At the same time, it acknowledges the need to achieve a balance between formal paid care and an infrastructure of informal care and community-based care (including workplace) options.

The DIG also recognises that any new support for people with disability needs to fit into the broader economic and social security framework. As a result, the cost of housing for people with disability has not been included in the NDIS proposal. Disability is only one of many reasons why some people are poor. Therefore, where people with disability cannot access private sector finance, the NDIS proposal has been structured to fit in with government-sponsored affordable housing schemes.

Compared to the existing pay-as-you-go system of welfare programs, the DIG thought it desirable to introduce some of the discipline and longer-term stability of the funded compensation systems. At the same time, it was seen as important to include people with pre-existing disability (that is, not just new incidences of disability).

Accordingly, the preferred coverage and funding option is one which assumes:

- introduction in 2011 to allow time for the proposed feasibility study;
- a coordinated service model providing care and support including respite, aids, equipment, transport assistance and a range of community and day programs;
- a cost model commitment based on the notion of 'reasonable need' for services; and
- funds are set aside each year to meet some of the future costs of care.

(For more information, see Appendix D)

The estimate of care and support was based on existing and emerging models in the disability sector. On this basis, \$100,000 per annum is a benchmark figure for shared 24-hour supported accommodation, \$50,000 is the approximate cost of a position funded under the attendant care program, and the lower tiers of \$25,000 and \$10,000 purchase a variety of personal and community support packages.

An amount of \$1,000 is allocated to lower level need and children but does not necessarily mean that these people will all receive one hour of support per week. Rather it would enable a significant budget (\$300 to \$400 million per annum) to be available to develop infrastructure, crisis and episodic support in a range of circumstances.

Costings

In the five years to 2007–08, the total cost to government of the Commonwealth State Territory Disability Agreement and the Home and Community Care program grew by an average of 4.8 per cent per annum in real terms. This growth in outlays is driven by an increase in demand for services, largely as a manifestation of unmet need and the increasing inability of informal carers to cope. Slowly but surely the unmet need is manifesting itself through creeping cost escalation in the existing system. A NDIS provides government with an avenue to take control of and steer this inevitability, while also driving increased efficiency and better outcomes for people with disability and their families.

PwC estimates that the preferred model described above would require additional funding in the first year of operation of \$0.97 billion, \$2.04 billion in the second year of operation and with proposed annual increases of 10 per cent to the full year additional cost of \$4.56 billion over current projected expenditure to 2020. Within a generation, NDIS expenditure would stabilise below the levels expected, if the current system continues to grow at the same rate.²⁴

There is also a range of potentially very significant offsets that would need to be taken into account in a full costing, including:

- **income support savings:** a NDIS will lead to better employment outcomes and a reduction in the number of people on the Disability Support Pension (DSP). On reasonable assumptions this could amount to a reduction in DSP recipients of 140,000 people within 10 years, implying an annual saving of \$1.6 billion at that time. There would be additional savings through reductions in Carer Payments;
- **health care offsets:** the calculations of the cost of a NDIS include \$2.34 billion for the costs of care of people with a variety of physical conditions including cancer that may be more appropriately met through the health system;
- **aged care offsets:** about half the people who now receive aged care incur their disability before the age of 65 and so, progressively, would be covered by the NDIS. While very small initially, in 2046–47, a NDIS could account for half of the aged care costs which are projected to amount to 2.0 per cent of GDP; and
- **lower homelessness and criminal justice costs:** better managed care and support should reduce the incidence of disability leading to homelessness, crisis accommodation, child protection system, drug and alcohol services, hospitalisation and imprisonment. This could generate savings of several hundred million dollars per annum over time.

The offsets to a NDIS are likely to build over time and provide long-term sustainability for Australia's disability support system. They are explained in more detail in the following pages.

Future offsets against the cost of a National Disability Insurance Scheme

The proposed feasibility study should examine the following likely impacts of a NDIS on government expenditure beyond the disability services system.

Income support savings: the cost of DSP, as at June 2008, was some \$8.8 billion per annum, in respect of over 700,000 recipients. There are about 70,000 new DSP recipients every year (across all age groups), and very few recipients leave, other than to move onto the Aged Pension.

Of the 500,000 people of working age with a severe and profound disability, an estimated 365,000 are not in employment, and presumably receive a DSP. A more active management and support model for people with a disability (including community and workplace responsibility and ownership), such as a NDIS, would improve employment outcomes for people with disability.

Currently, only around 2 per cent of people on the DSP each year cease receiving this payment without going onto another form of government income support. This may be contrasted with workers' compensation schemes that achieve much better rates of return to work. If the 'recovery rates' amongst people on the DSP could be increased to 4 per cent per annum, the projected number of people on DSP would be reduced by 140,000 in 10 years, which would be equivalent to a \$1.6 billion annual saving. These recovery rates have been shown to be achievable for even the most difficult long-term claims in worker compensation.

In addition to DSP, some \$2.7 billion per annum is paid in Carer Payment and Carer Allowances to people who support someone with disability. To the extent that employment outcomes are achieved for people with a disability, one could expect a proportionate saving for their carer responsibilities and improvement in their own employment prospects.

Moreover, in both of these cases, increased workforce participation would provide positive government revenue in taxation income.

Health care: it is estimated that by 2020, 80 per cent of Australia's healthcare costs will be consumed by people with chronic and complex health conditions requiring ongoing, long-term care. These are the same people who would be clients of a NDIS. Moreover, the bulk of this expenditure is on care rather than health.²⁵

The DIG's model includes a number of physical conditions that may be seen to be more appropriately treated in the health system. PwC's estimate of the costs of supporting people with these conditions when the scheme is fully operational is:

- Cancer – \$1.63 billion;
- Diabetes – \$0.38 billion;
- Cardiovascular (excluding stroke) – \$0.08 billion;
- Respiratory – \$0.10 billion;
- Inflammatory Bowel Disease – \$0.02 billion; and
- Genitourinary diseases – \$0.13 billion.

Therefore excluding these conditions or at least recognising that some of the costs are already being covered by the health system, would lead to a significant reduction (up to \$2.34 billion, or 20 per cent) in the estimated gross additional cost of a NDIS.

The scheme would make a substantial contribution to mitigating the economic and social burden of disease by providing appropriate care and support for people with severe and profound disability arising from chronic and complex diseases, and promoting a more active and healthier lifestyle.

Aged care: approximately 50 per cent of Australia's estimated 1.2 million people with a severe and profound disability are aged less than 65. Therefore, it is reasonable to assume that, in future generations, at least 50 per cent of people with a severe and profound disability aged over 65 will have incurred their disability before age 65, and will therefore become eligible for NDIS.

On this basis, a NDIS will ultimately be covering half the costs of aged care. DIG notes that some \$7 billion is currently spent on community and residential aged care, or about 0.8 per cent of GDP (in 2006–07). The government's 2007 Intergenerational Report projects this cost to move to 2.0 per cent of GDP by 2046–47. It is quite possible that 50 per cent of this burden could be funded by a NDIS at that time.

Homelessness and criminal justice: according to the Australian Bureau of Statistics there were about 105,000 homeless people on the 2006 Census night. People who have a mental illness, an intellectual or developmental disability, or a previous acquired brain injury were disproportionately represented in this group and many go through a vicious cycle of homelessness, supported accommodation, child protection system, drug and alcohol services, hospitalisation and imprisonment. People with disability and mental illness are over-represented in all these areas.

About 30,000 people consume some 45,000 episodes of supported accommodation per year in Australia and about 25,000 people currently reside in Australia's prison system. It costs about \$70,000 to \$100,000 per annum to house someone in prison—giving an estimated total prison cost of \$2 billion to \$2.5 billion per annum.

A well constructed program of intervention can achieve dramatic savings in both the social and economic costs of this system. For example, the Housing and Accommodation Support Initiative (HASI) in NSW achieved the following outcomes among its participants (110 people with mental illness and high levels of psychiatric disability):²⁶

- 81 per cent reduction in average time spent in hospital for psychiatric and/or emergency admissions per person per year (from 89 days to 17 days);
- 78 per cent reduction in average length of hospital stay (from 30 days to 7 days);
- 78 per cent reduction in rate of incarceration (from 30 per cent to 7 per cent);

- 30 per cent reduction in life skill related disability;
- 15 per cent reduction in psychological distress; and
- 40 per cent increase in Global Assessment of Functioning (occupational, social and educational).

The estimated recurrent cost of the HASI program was about \$57,000 per participant. This is comparable to the higher support levels proposed under a NDIS, but less expensive than the costs of incarceration or an average of 89 days in a psychiatric hospital. As an illustration, a 10 per cent reduction in the cost of imprisonment and hospital-based mental health would represent about \$200 million savings per annum.

It would therefore be reasonable to expect that a NDIS, with its planned and structured support for people with disability, will lead to significant savings in the hospital, judicial, homelessness and other social support systems.

Consistent insurance schemes

A NDIS should complement nationally consistent state/territory-based insurance schemes covering motor accident, workers' compensation, public liability (general injuries) and treatment injury.

A number of state/territory-based insurance schemes currently cover a range of injuries (most significantly traumatic spinal cord injury and brain injury) with wide differences in coverage and entitlement across jurisdictions and across cause of injury. About half the people traumatically injured at work, in traffic accidents, through medical incidents or in other specified ways (including sporting injury and assault), receive lifetime care and financial support through compensation schemes or through the litigation system. This is not available to people born with disability or acquired in other ways. Most of this injury insurance is paid in lump sums, and beneficiaries may also need to access the wider disability welfare system when their available reserves run out.

To ensure a comprehensive and equitable national approach, the various insurance schemes that provide lifetime care and support for traumatically injured Australians should extend to become no-fault and nationally consistent.

The Commonwealth and State and Territory Governments should work together in the context of the feasibility study to ensure that state-based accident insurance schemes are consistent with the proposed national scheme.

Providing Benefits for People with Disability Under the New National Disability Insurance Scheme—a Summary

The benefits of the proposed NDIS include:

- all people with disability would be entitled to an appropriate whole-of-life suite of services and support;
- people with disability and their families would have certainty and clarity about options from the point of determination of a disability;
- case management would be available to facilitate independence, maximise potential and work with individuals and families to plan transitions over their lifetimes;
- early intervention would be a top priority;
- training, development and access to work would build self-esteem and reduce long-term costs;
- families would be able to make choices about the combination of work and informal care for family members at various life stages, as in other families;
- an integrated system of funding, purchasing and delivering disability services would be available to Australians for the first time;
- the proposed scheme addresses the current unmet and under-met need for care and support, and the unsustainable reliance on carers; and
- the introduction of such a scheme would enable a range of innovative private investment opportunities to emerge.

Part 4: Ensuring Income Support is Adequate

Key DIG findings

Public policy should fully support the reasonable aspirations of people with disability for economic independence. For most Australians this comes through work, and so it should be for people with disability. However, for people unable to support themselves fully through employment, income support is vital.

Eligibility for the Disability Support Pension (DSP) is based on an assessment of impairment that prevents individuals from working or re-skilling for work. Like many other income support payments, DSP is provided as an entitlement—that is, if a person meets the criteria they receive the payment.

Once a person is eligible for DSP as an adult, the amount of payment does not vary in relation to the degree of impairment or life stage. It is assumed that other needs such as care and support, aids, equipment and transport are met through service systems administered separately in each State and Territory.

Over the past decade, Australia has seen a 35 per cent increase in the numbers of DSP recipients and a 395 per cent increase in Carer Payment recipients.²⁷ Nearly 43 per cent of people with disability have their primary income via a pension or allowance, compared with 13.6 per cent of the general population.²⁸

The Pension Review

The DIG strongly supported the work of the recent Pension Review as part of the Review of Australia's Future Tax System. The Review, led by Dr Jeff Harmer, Secretary, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), looked at measures to strengthen the financial security of seniors, carers and people with disability. The DIG urged the Pension Review to consider an adequate level of income support for people with disability and carers.

The background paper prepared by FaHCSIA for the Pension Review found that people on a DSP are among the poorest in the community and show greater signs of financial stress than single old age pensioners.

Disability leads to a much higher cost of living for many. During its consultations, the DIG repeatedly heard that ongoing costs of home modifications and purchase of aids and equipment drains the family budget. These items are not luxuries, they are necessities, and income support is not sufficient to provide an adequate standard of living for people with disability and their families. These additional costs vary considerably from person to person and so support needs to respond to individual needs.

The DIG notes the initiatives in the Commonwealth Government's 2009–10 Budget which arose from the Pension Review report. These initiatives related to increases for recipients of a DSP and Carer Payment under the Australian Government's Secure and Sustainable Pension Reforms.

Under the new arrangements the government will provide an additional: \$32.50 a week for single pensioners on the full rate of pension; and \$10.15 a week for pensioner couples. The government will also provide carers with a new annual Carer Supplement of \$600.

While these increases are welcome, the DIG believes that the adequacy of income support for people with disability and carers should continue to be closely monitored.

The DIG has not recommended inclusion of income support in a NDIS. However, as noted earlier, it would be useful for the feasibility study to consider this issue and whether there would be benefits in having a more fully integrated scheme.

Part 5: Improving Savings and Taxation Incentives for Privately-Funded Services

Recommendation 2

DIG recommends that the feasibility study into a National Disability Insurance Scheme includes further examination of the potential for any of the following measures to enhance additional private provision for people with disability.

- *Action on the recommendations of the Senate Standing Committee on Community Affairs in its report on Special Disability Trusts, Building trust: Supporting families through Disability Trusts, October 2008.*
- *Setting up a savings plan with incentives for family members to save for the short- to medium-term financial needs of a family member with disability.*
- *Removing taxes on essential goods and services required by people with disability, their families and carers.*
- *Introducing a Disability Support Tax Rebate into Australia's tax system to recognise the work-related costs of people with disability and carers.*
- *Development of private housing and services models that could complement a NDIS.*

This would require consultation with other parts of government, including importantly, the Review into Australia's Future Tax System.

Key DIG findings

The proposed new disability policy framework should include a number of measures to boost private savings, promote asset transfers, recognise the additional costs of people with disability, their families and carers and remove tax imposts which are inhibiting private provision.

The absence of an entitlement for care and support for people with disability has created barriers for private investment. Many creative options for private investment in housing flounder, for example, because there is uncertain and unreliable care and support. Families who are willing to provide for relatives with disability are often thwarted by the fragmented and uncertain service system.

Private investment will not and should not substitute for a basic level of individualised care for people with disability. A core system of entitlements, as proposed in a NDIS, would provide a strong platform for additional private contributions towards the care and support of people with disability. The final design and implementation of the following recommendations to promote private provision will depend on government progress towards establishing the scheme. Without the scheme, any supplementary measures will make a much less significant contribution to dealing with unmet need.

Special Disability Trusts

In September 2006, Special Disability Trusts (SDTs) were introduced to assist parents and immediate family members wanting to provide a financial contribution towards current or future accommodation and care of a family member with severe disability. SDTs were designed to allow families to make these contributions without reducing the person's entitlement to a DSP, the Age Pension, a pension from Veterans' Affairs, and related benefits. However, since then very few SDTs have been established.

In October 2008, the Senate Standing Committee on Community Affairs prepared a comprehensive report on Special Disability Trusts, called *Building trust: Supporting families through Disability Trusts*.²⁹ Its recommendations are shown in Appendix F.

The Committee had substantial concerns about the effectiveness of the current arrangements. They found that eligibility requirements are too restrictive so that many people with severe disability, including intellectual disability and disability resulting from mental illnesses, cannot benefit from the trusts. The Committee also said that the concessional limit on trust assets is too low and does not allow families and carers to provide effectively for the future.

The Committee also found that tax arrangements which currently apply to SDTs diminish their value for carers and people with disability. Applying capital gains tax to the sale of a beneficiary's primary residence and the high rate of tax applied to trust earnings are particular disincentives to investing in the trusts. A major shortcoming is the tight restrictions on uses of SDTs. People see little point in setting aside funds if they cannot use them to provide the accommodation, care and support that their loved one needs to live as independently as possible.

The Commonwealth Government's response in the 2009–10 Budget to the Senate Committee report on SDTs contains some initiatives that address barriers preventing families from making financial contributions to the care and accommodation needs of a family member with severe disability. These initiatives include the following:

- unexpended Special Disability Trust income will be taxed at the beneficiary's personal tax rate, rather than the top marginal tax rate, with effect from the 2008–09 income year;

- the sale of a residence owned by a Special Disability Trust and used by the beneficiary as their main residence will be exempt from capital gains tax, with effect from 1 July 2009; and
- the Special Disability Trust guidelines on care and accommodation expenses will be revised within current legislative provisions, to broaden the types of expenses that can be met from Special Disability Trust funds, and to provide greater clarity in regard to expenses that are allowable.

The DIG notes that there are other shortcomings of SDTs. Firstly they are a way of transferring assets rather than a way of promoting savings. Secondly, because SDTs are individual trusts they are expensive to establish and maintain as they need auditing, and they are likely to pay retail rather than low-cost wholesale fund management fees.

The DIG therefore examined whether SDTs could be extended to promote savings as well as asset transfers, and become integrated into the superannuation system to benefit from its economies of scale. However, because of the very specialised technology and operating rules that underpin the superannuation industry this is not practical.

The DIG also received submissions and heard during its consultations that families are willing to stretch themselves financially (as well as physically and emotionally) to support a family member with disability, provided it increases the prospect of improved and increased services. Changing SDT arrangements could:

- promote savings and asset transfers in low-cost ways;
- increase the available pool of private savings; and
- supplement government-funded support.

The DIG believes that further reform in relation to accessibility to SDTs should be considered. DIG recommends that the potential for SDTs to contribute to additional private investment in services, including further consideration of the Senate Committee's recommendations, should be considered as part of the feasibility study of a NDIS.

International savings schemes

A recent study to examine special savings schemes operating in other countries designed specifically to assist people with disability and their families found that only a small number of models exist and there is limited international experience on which to draw.³⁰ Indeed, Australia's development of SDTs was one of the few innovative models developed to suit the needs of people with disability and their families.

The research highlighted the types of incentives available or proposed by overseas governments to encourage private financial provision, including co-contributions or matched savings, tax deductibility for contributions, and tax exemption for income earned from savings.

While in Australia SDTs exist to assist families to privately fund the longer-term care and accommodation needs of a family member with disability, a savings plan option could provide an incentive to families who are less able to contribute to a mechanism such as a SDT. A new savings plan could also provide a way to save funds to purchase accommodation or support.

Four examples of overseas savings plans are documented which are highly adaptable to Australia.

International savings plan models

Savings Gateway (United Kingdom—starting up in 2010)

- Savings account for low income groups such as those on government benefits including Incapacity Benefit.
- Aims to help people save and improve financial literacy.
- Capped co-contributions by government after maturity at two years.
- Co-contribution amount and match rates yet to be determined.

The Child Trust Fund (United Kingdom—introduced in April 2005)

- Long-term savings and investment account to provide incentive for parents to save for their children and to encourage children to save.
- Initial endowment of £250, double that for low income; additional £500 at age 7; cannot be accessed until maturity when child turns 18.
- Parents, family and friends can make tax deductible contributions; earnings exempt from income tax.
- Operated by private sector financial institutions.

Financial Security Accounts for Individuals with a Disability (United States—a proposal)

- Special savings account with tax deductions for parents/carers of children with disability for contributions of up to \$US 2,000 per year, subject to income limits, for future expenses associated with a child's disability.
- Income tax-exempt and disregarded for pension entitlements.
- Capped at \$US 500,000 over a person's lifetime.

Registered Disability Savings Plan (Canada—implemented in 2008)

- Contributions (not tax deductible) with no annual limit, but a lifetime limit of \$CAN 200,000 to help parents and others to save for the long-term financial security of a beneficiary who has a prolonged and severe physical or mental impairment.
- Earnings generated from accounts are tax exempt.
- Matched government contributions up to \$CAN 3,500 per annum.

Features of a new Australian savings model

The features of an Australian savings plan model could include some of the following elements:

- tax-deductible contributions made by family members for the purpose of providing for the needs of their family member with disability;
- no annual contribution limit but lifetime contributions to be capped at \$200,000;
- earnings on the savings account to be tax exempt;
- earnings on the savings account to be exempt from the social security income and assets tests, or exempt up to a specified limit;
- matched government co-contribution for contributions over \$500 (matched dollar-for-dollar) up to \$3,000 per annum;
- withdrawals can be made at any age (of person with disability) after a specified period—for example two years; and
- withdrawals can only be used to meet expenses associated with the beneficiary's disability and can be contributed to a SDT.

The DIG recommends that any savings plan or further changes to SDTs should be considered together with the feasibility of a NDIS. This would ensure that arrangements would be as consistent and flexible as possible, and that any concessional treatment is well-targeted. Savings plans may not be cost-effective if set up in isolation or where they involve high compliance costs.

Incentives for additional private savings could make an important contribution to meeting the future costs of people with disability, in the same way as extra voluntary superannuation contributions are today adding to future retirement incomes.

Privately-funded services

In the health, education and aged care sectors, government-subsidised and private services operate side-by-side with government-only funded services.

In the disability sector there is currently no government-subsidised private system. For example, the DIG consultations highlighted that if a family wants to contribute to the costs of providing support and shared accommodation to a family member by buying or developing a purpose-built dwelling, and then seeks funding for care and support, they can be seen as 'queue jumpers'.

A number of people at the DIG consultations said that they were not looking for handouts from the government. What they wanted is a reduction in the bureaucratic barriers that prevent them from fully looking after their children.

However, private capital contributions are not very common. More generally, potential for families to maximise private contributions is hindered because a shared, two-tier model (together with supported savings mechanisms) is simply not available.

Private accommodation models

The DIG heard from a number of non-profit organisations about their innovative models to provide home ownership and/or supported accommodation for people with disability. This includes the Hope Australia Urban Village Model and Foresters Community Finance. *(For more information, see Appendix I)*

A joint submission was received from Foresters Community Finance and Parent to Parent Association QLD. The submission details a community economic development model to mobilise social investment in a trust structure to secure long-term affordable housing and support for people with disability. Foresters says that taxation and financial legislation, and regulation of community economic development companies and community development finance institutions, stunt the growth of such entities and thus inhibit private investment in the community sector. They argue for government to provide legislative and statutory support for these entities.

Hope Australia has developed a model in which a unit trust is established to enable the parent/carer of a person with disability to secure guaranteed accommodation for their adult child or person they are caring for who has an intellectual disability. Hope Australia is not looking for capital funding from government or additional benefits. They want to have existing government benefits, currently received by the parent/carer—namely Carer Payment, Carer Allowance and associated respite program funding—redirected to Hope Australia to pay for care and support through Hope Australia's proposed model.

Taxation incentives

People with disability often have a higher cost of living than other Australians because they need additional goods and services as a result of their disability. Tax paid on these goods and services imposes additional cost pressures. While all taxpayers are supposed to receive equal tax treatment, people with disability, and their families and carers tend to carry a higher tax burden because of their special needs and additional costs.

Under the *A New Tax System (Goods and Services) Act 1999*, a limited number of exemptions from the Goods and Services Tax (GST) currently apply to disability aids, equipment and home modifications and furniture. They are specified in the regulations and have to be specifically designed for people with illness or disability. There is no exemption for a large range of other items directly related to disability, such as non-slip floor coverings, extra cleaning services, storage facilities for wheelchairs, or requirements for proximity to specialist facilities such as spinal units.

PwC was commissioned to review current indirect taxes and identify any opportunities and means for reducing taxes on people with disability, their families and their carers. PwC prepared a table setting out current tax treatment and some potential measures to improve the application of the indirect taxes to people with disability. PwC also looked at GST, income tax, stamp duty and customs. *(For more information, see Appendix C)*

The DIG considers that PwC suggestions to limit the disproportional financial burden of the taxes on people with disability have merit. The suggestions include:

- extending GST exemptions;
- extending the medical expenses tax offset;
- changing the tax treatment of disability housing investments;
- extending vehicle registration concessions; and
- changing duty on imported vehicles, footwear, clothing and goods used extensively by people with disability.

To reduce the disproportional tax burden on people with disability and their families and carers, the current Review into Australia's Future Tax System should consider these and other ideas in the PwC report.

Costs of working

People with disability, their families and carers also face additional costs when they take up employment. Currently, there is little recognition in the taxation system of these costs, which can include additional respite and support services, aids and equipment.

The DIG recommends that the Commonwealth Government consider the option of introducing a Disability Support Tax Rebate to help remove barriers to employment and active participation by people with disability, their families and carers. The Review into Australia's Future Tax System should consider the merits of a rebate scheme.

The scheme would be similar to the Child Care Rebate, which is a non-means tested rebate for child care costs covering 50 per cent of out-of-pocket approved child care expenses up to the value of \$7,778 (indexed in line with the Consumer Price Index) per child per family per annum.

Similarly a Disability Support Tax Rebate could be applied to work-related expenses of disability aids, equipment, care or disability support necessary for working, studying and/or training.

A Disability Support Tax Rebate would interact with other current and proposed tax concessions and disability services and programs. In considering the interactions, it is important that the rebate is equitably and fairly available, and that people who get the rebate cannot claim for costs already reimbursed through other means, for example, aids and equipment schemes.

Section III: Other Recommended Areas for Action to Increase Investment in People With Disability

Part 6: Providing More Housing for People with Disability

Recommendation 3

DIG recommends that regulations for accessible and adaptable housing standards be strengthened to facilitate ageing in place; and as a first step, a set of no-cost and low-cost requirements be mandatory in all new residential buildings.

Recommendation 4

DIG recommends that the National Rental Affordability Scheme be amended to better meet the needs of people with disability by:

- *increasing the payment made in relation to housing for people with disability to recognise the higher costs of providing and servicing their housing (NRAS Plus); and*
- *setting minimum adaptability and accessibility standards at least equal to the no-cost or low-cost standards in Recommendation 3.*

Key DIG findings

Of all disability services, the most significant unmet demand and the greatest anxiety for families relates to housing and accommodation.

Most people with disability face significant challenges securing private housing. This is because the disability housing sector is not sufficiently profitable to attract purely commercial investment. People with disability usually have to rely on the capabilities, resources and determination of their own families or groups of parents to develop solutions.

Traditional approaches to housing support for people with disability have tended to result in disjointed housing services and support. Housing often reaches a crisis point when informal care is no longer available, such as when a family carer dies.

The Commonwealth and State and Territory Governments provide significant funding for community and public housing for people with disability. People with disability

constitute an increasing proportion of those in public housing, from just over 20 per cent in 2001–02 to almost 40 per cent in 2005–06.

The Commonwealth Government also pays income support supplements to those in the private rental market, for example, Rent Assistance payments from Centrelink.

Governments fund shared supported accommodation under the National Disability Agreement, with costs of the dwellings met through a mixture of government funding, contributions from disability organisations, philanthropy, and fund raising by parents and other supporters. Occasionally, families can also access government funds to contribute to home modifications so that a person with disability can be cared for at home.

Developing housing stock for people with disability has traditionally happened as part of the disability service system, rather than as part of a broader approach to affordable housing. This specialised approach initially led to accommodating people with disability in large institutional homes. In recent decades, Australia has seen a shift towards shared accommodation models distributed through the broader community and more innovative models of accommodation.

The quality of care and support within current shared and supported accommodation may also not meet expectations. Because of shortages, people can find it difficult to contest or question service providers that deliver part or fully-funded accommodation. This often leads to 'client capture'.

An alternative approach is to provide more choice, by separating the care and support from the physical infrastructure or dwelling. This recognises that preferred suppliers of accommodation and care and support to people with disability may not be the same organisation. In this alternative framework, providing housing should form part of an affordable housing strategy because disability is just one among many possible causes of poverty. However, the housing must be accessible.

Building regulations

Urgent government action is needed as voluntary building standards for accessible and adaptable housing have failed to ensure that most new dwellings are suitable for people with disability, despite the predicted rapid increase in the proportion of the population with disability over the next 40 years.

Mandatory national building standards are needed, which specify design principles and requirements that accommodate people with disability and facilitate ageing in place. This recognises that as people age they will acquire disability and that by 2051, 27 per cent of the population will have disability.

The DIG recommends that as a first step, a set of no-cost and low-cost requirements become mandatory in all new residential buildings. A minimum set of requirements would include:

- a continuous accessible path of travel from a parking area or allotment boundary and a level entry into the home;

- a bathroom on the ground floor with reinforced walls, to allow for future adaptation and a hobless, step-free shower recess;
- external and internal doorways with a minimum 850mm width;
- corridors on entry level with minimum 1,000mm width;
- space on the ground floor capable of use as a bedroom and living area; and
- a kitchen area capable of adaptation to provide sufficient turning space between benches.

National Rental Affordability Scheme

The recently introduced National Rental Affordability Scheme (NRAS) could help lift the level of private investment in housing for people with disability. Under the NRAS, private investors receive tax incentives to build new affordable rental properties. However, the DIG recommends a number of refinements to improve the scheme's responsiveness to people with disability.

Given the additional costs for establishing disability accessible or adaptable accommodation, and the higher ongoing costs of managing tenancies involving people with disability, applying the standard level of incentive to housing for people with disability will not necessarily attract any additional investment in appropriate disability housing.

Consistent with the Commonwealth Government's social policy objective of improving the housing and other circumstances of people with disability, it is important that the NRAS is modified to reflect the higher costs of housing for people with disability. One approach would be to set an additional level of subsidy in return for a guaranteed minimum number of people with disability housed on a project-by-project basis.

The DIG notes the target of 50,000 affordable rental dwellings by 2012 and short timetable for expressions of interest and lodgement of tenders. Therefore, a trade-off is likely between meeting the volume targets and adaptability and accessibility standards, given that much of new housing stock currently under construction is not properly accessible.

Given the ageing population and people acquiring disability as they age, and the social and economic benefits of people ageing in place, it is vital that new housing stock built through the NRAS is accessible and should at least conform to the minimum set of building regulations outlined above.

The DIG notes that eligibility for NRAS is modelled on eligibility for Commonwealth Rent Assistance or for the low income Health Care Card. The DIG suggests looking again at the eligibility provisions for tenancy under the scheme, particularly as they relate to people with disability who have taken up employment. Otherwise, this group will face even higher effective marginal tax rates if they enter the workforce. In this

way, the NRAS may unintentionally act as a further barrier to the employment of people with disability.

The DIG made these suggestions to FaHCSIA in May 2008, in response to the NRAS technical discussion paper. (*A copy of the letter is at Appendix H*)

Social Housing Initiative—Nation Building – Economic Stimulus Plan

In February 2009, the Commonwealth Government also announced the provision of additional funding for social housing under the Nation Building – Economic Stimulus Plan. This initiative will provide funding of \$6 billion over three and a half years from 2008–09 to 2011–12 for the construction of new social housing and a further \$400 million over two years for repairs and maintenance to existing public housing dwellings. It is being conducted in partnership with the State and Territory Governments. It will provide a boost to public housing and housing administered by the not-for-profit community sector and is designed to assist low income Australians who are homeless or struggling in the private rental market.

The DIG notes that under this initiative, Commonwealth guidelines include a requirement that most constructed dwellings adhere to universal design principles that facilitate better access for people with disability and older people. Additionally, the government is targeting a higher level of adaptability in at least 20 per cent of these dwellings which will need to meet the Australian Standard for Adaptable Housing AS4299–1995, Class C.

Designed to increase affordable housing supply, these new schemes have the potential to contribute to meeting the housing needs of people with disability, provided the housing is accessible. This highlights a broader housing policy issue. Despite a voluntary disability access and adaptability building code, most new private dwellings are not accessible or adaptable. This policy failure contributes to increased costs in the long-term, especially as the proportion of the population with disability will increase rapidly over the next 40 years. The policy is also inconsistent with ageing in place objectives.

Part 7: Offering Better Employment Opportunities

Recommendation 5

DIG recommends a change of focus for Disability Employment Services (formerly Disability Employment Network) to direct candidates with disability into the mainstream recruitment market, rather than act as employment agencies in their own right; and to ensure that services are appropriately targeted and delivered in a way that the private sector will access them.

DIG also recommends that access to funded services in the Disability Employment Services be available to people in Australian Disability Enterprises who want to take up employment in the open labour market.

Key DIG findings

Australia is not performing well in assisting people with disability to benefit from employment. Not only is Australia's rate of workforce participation by people with disability lower than most Organisation for Economic Co-operation and Development (OECD) countries, Australia's rate is actually declining while the employment rate of people with disability in like countries is increasing.

The OECD recently noted that Australia's employment rate for people with disability is disappointing, given the growth of our economy over recent years.

The OECD ranked Australia:

- 13th out of 19 countries on the employment rate for all people with disability; and
- lowest of 16 countries on the percentage of people receiving disability related benefit while they were also employed (only 11 per cent of people receiving these benefits were in employment in Australia).³¹

The labour force participation rate of Australians with disability in 2003 was 53 per cent, compared with 81 per cent for people without disability. The unemployment rate was 8.6 per cent compared with 5 per cent for people without disability.

People with a profound level of core activity limitation had a much lower labour force participation rate (15 per cent) and a higher unemployment rate (14 per cent).

The labour force participation rates for people without disability rose from 76 per cent in 1988 to 81 per cent in 2003. However, for people with disability there was little change over this period with participation rates remaining between 51 and 53 per cent.³²

In Australia, only 35 per cent of people with disability receive their primary income through a wage, compared with 63 per cent of people without disability. In 2003, the median gross personal income per week of people aged 15–64 years with a reported disability living in households was \$255, compared with \$501 for people without disability. Median gross personal income per week decreased with increasing severity of disability, being lowest (\$200 per week) for people with a profound core activity limitation.³³

Increasing the ratio of disabled-to-abled incomes in Australia to OECD average levels would represent an additional \$14.3 billion in yearly income.³⁴

Improved participation in employment by people with disability would also flow on to improved participation by carers who also experience lower employment outcomes than other Australians. In the 2003 Survey of Disability, Ageing and Carers, almost two-thirds of all carers aged 15–64 years were employed (1.3 million people) compared with 73 per cent of non-carers. Of these employed carers, around 790,000 were employed full-time and a further 473,000 part-time. Around 48 per cent of primary carers of this age were employed and these carers were more likely to work part-time than full-time. This is consistent with the intensity of care provided by primary carers, who may find it more difficult to combine their caring role with paid employment. Of carers aged 15–64 years, around 79,000 were unemployed, and a further 660,000 were not in the labour force.

Access

Access to buildings is a fundamental issue for people with disability seeking employment. The DIG notes that in December 2008, the Federal Attorney-General, the Hon Robert McClelland MP, and the Minister for Innovation, Industry, Science and Research, Senator the Hon Kim Carr, tabled the draft *Disability (Access to Premises – Buildings) Standards* (the Premises Standards) in Parliament. The draft was referred to the House of Representatives Standing Committee on Legal and Constitutional Affairs (the Committee).

On 15 June 2009, the Committee tabled its report on the Premises Standards entitled *Access All Areas*. The Commonwealth Government has indicated that it is considering the report. Action on these standards has been a long time coming. Since 2000 when the *Disability Discrimination Act 1992* was amended to give it the power to develop a Standard on Access to Premises, there have been various drafts and consultation processes.

The DIG urges the Commonwealth Government to resolve these issues as quickly as possible and to ensure that fair requirements for access to public premises for people with disability are not compromised by cost concerns.

Business case

Despite this poor national record, there is a clear business case for hiring people with disability, which includes many benefits. The Australian Employers' Network on Disability recently released *'Opportunity', the business case for including people with disabilities as customers and employees*, with details available on their website at www.emad.asn.au.

Many Australian and international examples show that employing people with disability can lead to increased productivity, reduced absenteeism, reduced turnover, increased morale, more positive organisational culture and reduced workers' compensation. As the population ages and skills shortages emerge, there is a greater imperative to use the entire potential workforce. In addition, people with disability and carers represent a largely overlooked multi-billion dollar market segment.

Employment services

As well as mainstream Job Network Services, Disability Employment Services (DES) (formerly known as Disability Employment Network) are funded to provide assistance to people with disability to find and keep work. A network of organisations delivers this support around Australia.

A job seeker can be referred to DES if they have a permanent (or likely to be permanent) disability; have a reduced capacity for communication, learning or mobility and require support for more than six months after placement in employment.

The DIG notes that from 1 March 2010, existing caps on disability employment services will be removed and for the first time, all job seekers with disability will have access to individually tailored employment services while employers will have access to greater support.

The Commonwealth Government also funds supported employment places for people with disability in businesses, including in packaging, horticulture, animal husbandry, laundry, catering and woodwork. Australia-wide, there are more than 18,000 people with disability working in around 362 of these business service outlets, now known as Australian Disability Enterprises.

Employers' views

A significant barrier for people with disability is the attitudes of employers. A recent study of the views of private sector employers in small and medium size enterprises (SME) about the employment of people with disability found that there is an openness to consider people with disability, but there is little awareness of them.³⁵ Employers in the SME market use mainstream recruitment agencies to find staff and rarely find candidates with disability included in fields. SMEs also have strong negative views about dealing with government and they are reluctant to engage with government agencies when it comes to the recruiting staff.

Employers expressed concerns about perceived risks of employing people with disability, including workplace safety issues. This is despite evidence that people with disability have a lower number of occupational health and safety incidents compared with employees without disability, and that workers' compensation costs are also lower for people with disability compared with other employees.³⁶

In the disability employment sector, the research found a complex array of specialist providers (DES), government agencies, studies and resources, a lack of focus on the basic business needs of employers (finding the best person for the job as quickly as possible), and an overly internal focus on the activities within the disability sector.

There are some excellent programs and ideas available, however, employers were unaware of these. While SMEs appear to be open to considering people with disability, that potential workforce is not on their radar. There needs to be a more active 'selling' of the benefits of employing people with disability. SMEs also need assurance that additional support services are available when employing a person with disability.

Both the disability sector and governments could be significantly more effective when it comes to working with SMEs. To improve the employment of people with disability in the private sector, there must be greater understanding of the issues faced by these employers and they must be seen as valued partners. The DES should target and deliver their services in a way that more effectively engages the private sector.

The DIG believes that people with disability are likely to have more employment opportunities with mainstream recruitment agencies because these are the agencies that employers approach when looking for staff. DES should work with mainstream agencies to improve their capacity to market candidates with disability. It seems more appropriate for DES to direct candidates to these agencies rather than acting as recruitment agencies in their own right. This may also be less stigmatising for people with disability if the appropriate assistance is available.

Disclosure of disability to recruiters is also an issue. Many people do not reveal their disability for fear of discrimination or exclusion from consideration. There is no legal obligation to disclose unless it is likely to affect job performance or ability to work safely.

It is important that education and information activities continue to promote positive employer attitudes to the employment of people with disability.

Moving from Australian Disability Enterprises to open employment

The DIG also heard feedback during its consultations about people wanting to make the transition from Australian Disability Enterprises (previously known as Business Services or sheltered workshops) to open employment.

Currently, people working in these enterprises who want to try working in open employment are guaranteed that they can return if they find that open employment does not suit them. This guarantee helps people to try and succeed in open employment. However, people in Australian Disability Enterprises are not eligible to use a DES to help them prepare for or find and keep work.

In the interests of giving people with disability the best opportunities to participate in the open labour market, the DIG recommends that this exclusion from DES is changed, and that people in Australian Disability Enterprises are not required to give up their positions before they can use a DES.

National Mental Health and Disability Employment Strategy

The DIG notes that the Commonwealth Government is currently developing a National Mental Health and Disability Employment Strategy and supports the proposed actions to overcome shortcomings of the disability employment services system identified in the recent consultations. These include:

- improving disability employment services;
- providing greater encouragement, assistance and support for people with disability wishing to re-enter the workforce;
- encouraging innovation;
- tackling employer misconceptions;
- increasing Australian Public Service employment of people with disability; and
- improving access to education and training.

The 2009–10 Budget included \$6.8 million to establish an Employer Incentive Pilot to support ongoing employment opportunities for up to 1,000 DSP recipients as part of the Strategy. Employers will be eligible for an employment incentive of up to \$3,000 for each participant who undertakes ongoing employment for a minimum of 8 hours per week for 26 weeks.

Part 8: Building Research and Best Practice

Recommendation 6

DIG recommends that the Commonwealth and State and Territory Governments allocate \$30 million per annum under the new National Disability Agreement to fund a National Disability Research Institute as a centre of excellence to lead and promote disability research in Australia. The National Disability Insurance Scheme would be expected to maintain and expand this research.

Key DIG findings

In trying to understand the current situation for people with disability in Australia, the DIG found a disturbing lack of useful data and low investment in research on disability issues.

The Australian Institute of Health and Welfare found an overall lack of comprehensive data in non-government disability databases. *(For more information, see Appendix G)*

While disability data appears to be slowly improving, what is currently available and planned is still inadequate for robust policy analysis and development.

One of the advantages of moving to a NDIS would be the development of a comprehensive longitudinal database. A key plank of insurance-type schemes like this is the collection and analysis of data to help manage scheme liabilities.

During its work, the DIG found pockets of valuable research on disability issues being conducted across the country. Overall, however, disability research in Australia appears scarce, limited in scope, not always identified as disability-related, uncoordinated and poorly disseminated.

Governments in Australia spend over \$25 billion on disability each year. Yet there is virtually no investment in disability-related research. The previous Commonwealth State Territory Disability Agreement spent less than \$400,000 a year on research from 2002 to 2008. Under the new National Disability Agreement, Disability Ministers have agreed to contribute a total of \$10 million over 5 years from the Agreement for research in this area.

This is a considerable improvement but more investment is needed in research directly related to the lives of people with disability. The research can then be translated into evidence-based policy and best practice. This new research effort should cover the broadest practical range and encompass policy-relevant social research, practice research, engineering and technology, and medical research.

There is potential for strong partnerships with non-profit disability service providers, the corporate sector through its corporate community investments, between

researchers and industry, and with the philanthropic sector to ensure the commercial application of innovative ideas.

The DIG recommends the establishment of a National Disability Research Institute as a centre of excellence for disability research in Australia and proposes a charter for the institute. *(For more information, see Appendix J)*

Funding for the centre could come from a NDIS if that model is adopted. In the mean time, the centre could be set up with a contribution from the Commonwealth and State and Territory Governments as part of the National Disability Agreement.

Endnotes

- ¹ PricewaterhouseCoopers (PwC) 2008, *National Disability Insurance Scheme Final Report*, p.1.
- ² Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers: Summary of Findings*, cat. no. 4430.0, ABS, Canberra.
- ³ Australian Institute of Health and Welfare (AIHW) 2007, pp. 87–8.
- ⁴ AIHW 2007, p.119.
- ⁵ PwC 2008, p.31.
- ⁶ AIHW 2008, *Disability in Australia: trends in education, prevalence, employment and community living*, AIHW Bulletin, no. 61, pp. 28–9.
- ⁷ ABS 2003.
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- ⁹ Australian Institute of Family Studies (AIFS) 2008, *The nature and impact of caring for family members with a disability in Australia*, research report no. 16, AIFS, Melbourne.
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- ³² ABS 2003.
- ³³ ABS 2003.
- ³⁴ The Allen Consulting Group 2008, *Encouraging private investment in disability accommodation and services*, p.36.
- ³⁵ ADC Associates 2009, *Increasing the Employment of People with Disability in Small and Medium Enterprise: A Discussion Paper*, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).
- ³⁶ Australian Safety and Compensation Council 2007, 'Are people with disability at risk at work?.'

Appendix A

Disability Investment Group Terms of Reference and Membership

Terms of Reference

- Identify international best practice in leveraging greater investment in disability support.
- Identify opportunities to increase private sector involvement and investment in the funding of disability services and related infrastructure, including new innovations to develop alternative funding sources and arrangements for people with disability and their families.
- Identify barriers to this and how they might be overcome.
- Identify current and potential avenues for philanthropic investment in disability support.
- Explore government assistance to encourage family and private investment in the provision of housing, education, employment, equipment and other support for people with disability.
- Consider, with the community and financial institutions, avenues for new products and services to assist families plan for the future of their child with a disability.
- Develop options for investment in housing for people with disability through private and shared equity.
- Develop ways to assist people with disability, their families and not-for-profit organisations to engage with the private sector to enable development of accommodation and support options.
- Identify research reforms to encourage private sector engagement in research.

Members

Ian Silk, Chief Executive, AustralianSuper (Chair)

Bruce Bonyhady, President, Philanthropy Australia, Chairman, ANZ Trustees Limited and Chairman, Yooralla

Allan Fels AO, Professor, Dean of the Australian New Zealand School of Government, and former Chairman of the Australian Competition and Consumer Commission

Bill Moss AM, Chairman, MossCapital. Founder and Chairman, FSHD Global Research Foundation

Mary Ann O'Loughlin, Executive Director, The Allen Consulting Group (until October 2008)

Kathy Townsend, Kathleen Townsend Executive Solutions Pty Ltd

John Walsh, Partner, PricewaterhouseCoopers

Appendix B

Proposed Terms of Reference for a Feasibility Study of a National Disability Insurance Scheme

The Terms of Reference for a feasibility study of a National Disability Insurance Scheme should cover three principal areas:

- the policy framework, governance structure and prudential management of the scheme;
- scheme care and support management; and
- scheme assessment and review requirements.

Within each of these key areas there will be a number of matters to consider.

Policy Framework, Governance Structure and Prudential Management

- Policy framework (consider and further develop the three pillar policy framework (recommended by the DIG);
- governance options, (consider a range of governance options and their advantages/disadvantages, drawing on international and Australian experiences);
- cost modelling (develop a detailed demand and utilisation model, extending the work of the DIG and conducting a needs/gap analysis);
- revenue modelling (consider a range of options for funding the scheme, including alternative revenue sources, and develop projections based on a range of economic and demographic forecasts);
- data and research requirements (develop data collection requirements across different disability types and needs, so as to develop a strong evidence base to support scheme governance, to manage scheme utilisation and outcomes and to underwrite continuous improvements and efficiency gains);
- investment management (investigate investment management options, including potential links to the Future Fund and superannuation);
- insurance concepts (explore advantages of the insurance model of risk sharing, liability management and prudential oversight);
- State and Territory compensation scheme reform (consider and develop options for reform of state/territory-based compensation schemes to provide a consistent national and holistic insurance policy framework);
- law reform (consider reforms to State and Territory compensation laws to facilitate the introduction and operation of a NDIS);

- public/private schemes (consider the roles of the public and private sectors in the insurance and investment operations of the scheme); and
- transition (develop transition options for each State and Territory towards a nationally consistent approach, given different policy developments to date in each jurisdiction).

Scheme Care and Support Management

- Network development options (consider the required service provision network infrastructure requirements of the new scheme and develop options for transitions from the existing State structures);
- care and support requirements (for people with disability, their families and carers consider the types and range of services required, based on expected needs and demands);
- lifetime approach (investigate how best to take account of changing needs of people with disability and their families over their life course);
- individual planning and monitoring (consider how individual client potential can best be realised through personal planning, individualised services and outcome monitoring);
- labour force participation (consider arrangements to build employment opportunities for people with disability, their families and carers);
- case management (investigate insurance-type models of case management, care coordination and individual plan monitoring);
- service provider development (consider the industry structure and how service providers can be developed and strengthened as part of the new scheme to best meet its requirements); and
- workforce development (determine workforce needs to deliver expected outcomes and investigate options to develop and train this workforce).

Scheme Assessment and Review Requirements

- Needs assessment (establish the types and quantum of care and/or support requiring coverage and support by the scheme);
- expert panel engagement (assemble recognised experts on linking needs and demand to measurable outcomes to assist with scheme design and management);
- functional assessment (explore suitable classifications and instruments establishing eligibility and levels of care and support);
- needs management (explore operational issues related to assessments and utilisation of services, including feedback for claims management purposes);

- appeals and review mechanisms (explore issues around the nature of review and appeals, including the structures and experiences in similar schemes); and
- sensitivity testing (link different eligibility and entitlement options with service options and cost and liability modelling).

Stakeholder Engagement and Consultation

In addition to the key areas of review, the feasibility study will need to engage and consult with a wide range of stakeholders.

The key stakeholder groups should include:

- people with disability (peak advocacy bodies and individuals, whose needs and care are at the centre of the new support framework);
- National People with Disabilities and Carer Council;
- carers (peak bodies and carers representing the needs and interests of providers of unpaid care to people with disability);
- Commonwealth Government (the central agencies, including Prime Minister and Cabinet, Treasury and Finance, and the human services agencies, including Families, Housing, Community services and Indigenous Affairs, Health and Ageing, and Education, Employment and Workplace Relations, as well as other agencies as appropriate);
- States and Territory Governments (the equivalent central and human services agencies to the Commonwealth, as well as State accident compensation, civil liability and health care liability authorities);
- other government enquiries (for example, the Henry Review of Australia's Future Tax System and the National Disability Strategy);
- service providers (peak bodies and agencies engaged in service delivery across the disability sector);
- multi-disciplinary specialist disability teams (doctors, physiotherapists, occupational therapists, speech therapists, disability care workers, case managers, etc); and
- academics and research groups (specialist research groups in disability).

Given the need for both wide and extensive engagement it will be necessary, at the initial stage, to develop a stakeholder engagement plan in order to determine with how and when it will be best to consult.

The feasibility study should be led by a specialist taskforce drawn from across government and including specialists from outside government and its work should be supported by a dedicated specialist secretariat.

Appendix C

Executive Summary of the PwC Report on a National Disability Insurance Scheme

The case for change

Care and support and related services in Australia for people with disabilities are currently provided predominantly by a combination of an insurance system which provides fully-funded lifetime care benefits for eligible claimants, and a social welfare system comprising a wide range of Commonwealth and State/Territory-based programs.

Both systems are in urgent need of reform.

In the case of the insurance system, which predominantly covers a range of injuries, the most significant of which are traumatic spinal cord injury and brain injury, there are wide differences in coverage and entitlement across jurisdictions and across cause of injury. Moreover, because much of this insurance is paid in lump sum form, beneficiaries typically double dip into the wider disability welfare system when their available reserves are extinguished.

In the case of the disability welfare system, Australian governments commit a very large quantum of revenue—approximately \$20 billion per annum in total, of which about \$8 billion is on community care and support. In addition, nearly \$3 billion is paid to family and other informal carers. The bulk of the remainder (about \$9 billion) is paid in income support for about 700,000 Australians with a work incapacity.

In spite of this significant budget, there is a large and expanding unmet need for care and support, and also a large volume of unpaid care and support provided by family and other informal carers—an estimated 2.5 million people providing nearly 650,000 full-time equivalent carer positions (implying a replacement value of \$35 billion to \$40 billion per annum).

Further, beyond the recognised disability welfare system, people with disability consume a disproportionate amount of services of other types:

- of Australia's \$100 billion annual health expenditure, an increasing amount (projected to reach 80 per cent by 2020) is spent on people with a chronic or complex disease—people most likely to also have a disability; and
- people with a mental health condition and/or a previous acquired brain injury represent a high proportion of Australia's 25,000 prison population (which costs approximately \$2 billion per annum) and also Australia's homeless population (which costs at least \$150 million per annum).

The ageing population is applying significant pressure to this balance of care and support provision, a pressure which will continue for many years. The main foci of this pressure are found in the following areas:

- a primary focus because of the strong correlation between age and disability—over the next 40 years there will be a steady increase in the number of people with severe and profound disability (projected to rise from 1.4 million to 2.9 million) and an increase in the proportion of the population with severe and profound disability (from 6.7 per cent to 10.2 per cent);
- a secondary focus because of the ageing of the informal carer population; hence their inability to continue in their caring roles. This dynamic is magnified because of the gearing impact of informal care—for example, because non-paid care provides far more support than formal paid care, a 10 per cent reduction in the provision of informal service provision translates to a far higher percentage increase in the need for funded services to achieve the same overall level of support;
- an escalation in the likelihood of diminishing informal care because of reducing core family size and increased female workforce participation (these are currently the predominant sources of informal care);
- further pressure on informal carers due to the poor financial and mental and physical health-status outcomes associated with this role; and
- an expectation that the 'baby boom' generation will be far more assertive of their right to a life with dignity, including a reasonable and planned structure of formal care provision, compared to the provisions of the current model, which is one driven by informal care until there is a need for crisis intervention and management.

It is therefore inevitable that major escalation of the formal cost of the disability system will emerge over the coming decades, probably at a level of between 5 per cent and 10 per cent per annum in real terms, depending on the speed of deterioration in the informal sector and the expectations of the baby boom generation of people with disability. There is a strong social, political and economic argument that the required funding increases to meet this cost should occur in a planned and structured manner, one which may mitigate or defer at least part of this increasing need by achieving better outcomes through need management (including prevention) and service efficiency.

An insurance solution

As discussed in the *Australia 2020 Summit*, there is a view that the most appropriate way to satisfy the requirements of planning, efficiency and positive outcome realisation is through a social insurance type approach.

An increasing number of European economies (where the ageing population has bitten earlier and more severely) have been moving to this approach over the past decade or two, predominantly to formalise the revenue requirements of the welfare system.

In Australia and New Zealand, however, the best indicators of potential success of this approach are available through the funded (partially or fully) accident compensation schemes (workers' and motor accident compensation in particular).

The majority of these schemes have been and continue to be reformed over the past twenty years. Characteristics of the reform with respect to care and support of people with major injuries typically include:

- elimination or severe restriction in the availability of litigation as a pathway to compensation—and replacement with readier admission of eligibility on a “no fault” or “provisional liability” basis;
- replacement of inappropriate mechanisms of assessing monetary entitlement with mechanisms based on functional need, attached to a personal plan and expectation of mutual obligation and personal outcomes; and
- far more sophisticated governance models, which increasingly consider both financial and service utilisation (prudential governance) but also rehabilitation, health, return to work and other social outcomes of beneficiaries.

It is proposed that a model that is developed from elements of schemes such as these could be applied to the system of care and support for people with disability, and could be implemented in a coordinated way as follows:

- work towards developing a National Disability Insurance Scheme (NDIS) over a period of feasibility testing, which would include concept development, detailed analysis, stakeholder communication and structure and governance development; and
- as part of this initiative, seek collaboration between the Commonwealth, States and Territories to work towards a comprehensive and national approach to providing care and support for people who sustain catastrophic traumatic injury. Such an approach would encourage modification of existing statutes of worker compensation, motor accident compensation, civil (public) liability (extended to general injury) and medical indemnity (extended to treatment injury).

The feasibility, costing, funding options and governance of a NDIS are the primary focus of this report. This analysis extends previous work begun in 2005 with a report to the Insurance Ministers' Council¹ and re-engagement by the current Commonwealth Government.

¹ PricewaterhouseCoopers, 2005. Long Term Care: Actuarial Analysis on Long Term Care for the Catastrophically Injured

International comparisons

In considering the potential of the insurance model, we have referred to three relevant examples of social insurance schemes in other countries (Germany, Singapore and New Zealand) and where possible discussed them in the context of the Australian setting.

These three schemes provide examples and precedents for the model proposed in this paper.

The German scheme provides an example of a clear recognition of the cost burden of an ageing population, and an attempt to fund and manage this burden within an insurance type context.

The Singaporean scheme provides one approach to dealing with a comprehensive funded model underpinning social security, retirement savings and health care.

A particularly relevant feature of the NZ ACC scheme is the fact that over recent years, the scheme has faced severe pressure from cost and liability escalation in their serious injury cohort. This has necessitated the reviewing of the serious injury governance and service delivery model to one which is far more focussed on outcomes and evidence-based.

Structure and governance

A crucial aspect of a successful and efficient welfare system is a robust structure and governance model.

There are multiple problems with the current disability system, including:

- lack of central planning, historically-based funding models, and little opportunity for acknowledgement of community need;
- as a result, significant and unsustainable unmet and under-met need;
- lack of a clear definition on entitlements and eligibility for services, including links to other government services;
- many agencies involved (across both Commonwealth and State);
- little useful information to allow a planned and coordinated approach;
- even if information were available, no mechanism for reporting it or making the system accountable; and
- accordingly, poor monitoring of service providers with respect to both service delivery and outcomes.

It is argued that a properly funded NDIS model can assist across this range of problems by:

- applying an initial discipline of needs analysis at an aggregate level to estimate the funding required to equitably provide services to those most in need;
- introducing a regulatory process for achieving an agreed approach to assessing eligibility and entitlement within a model which recognises individual potential and planning for people with a disability;

- establishing clear protocols for links with associated government services;
- establishing clear guidelines and expectations of service providers, including requirements of reporting and accountability;
- establishing a comprehensive longitudinal unit-record database which allows monitoring of expenditure, service provision and outcomes of scheme beneficiaries;
- operating under a formal and independent governance model comprising a prudential board and an advisory council of stakeholders;
- sponsoring applied research to achieve innovation and best practice in service provision; and
- sponsoring required industry initiatives to ensure sustainability in the system (for example, at present in the need for a workforce strategy).

Coverage and Cost of an Insurance Solution

Coverage

At present the Australian disability system operates within a planning framework which could be significantly enhanced through greater investment in a concentrated plan for data management and reporting. Any attempt at detailed analysis of need or supply of disability services requires a range of triangulations of incomplete datasets, none of which were specifically designed for this purpose.

After consideration of the emerging data and an iterative discussion process with the Disability Investment Group (DIG), it has emerged that the target group for a NDIS should be people who need help always or frequently as a result of their disability, as determined by a set of consistent eligibility criteria to be developed. For the purposes of estimating this population in the current report, this population has been based on those with a severe or profound core activity limitation (as defined by ABS), with age at onset up to age 65. A NDIS should cover care and support and related services on a needs basis for this population, for life, with the exception of people who would become eligible for residential aged care by reason of functional deterioration due to ageing.

The 2009 prevalence (including one year of new incidence) of this population is about 600,000, with condition groupings as follows:

- congenital anomalies and intellectual disability (82,000);
- nervous system disorders (41,000);
- injury (15,000);
- mental illness (206,000);
- sensory conditions (12,000); and
- physical conditions (223,000).

Further discussion will be required concerning the extent to which all of these conditions (particularly some of the physical conditions where the care required is very illness-related) are appropriately funded by a disability insurance system rather than the formal health system, or alternatively may be entitled to offsets from that system. The use of detailed Burden of Disease data in this report allows relatively straightforward testing of options.

Considered by severity of support need, the distribution includes:

- constant support need (40,000);
- frequent support needs (104,000);
- regular support needs (32,000);
- Grade B lower support need (86,000); and
- Grade C lower support need (316,000).

Over the long-term projection period considered in this report, the total prevalence of the covered population significantly increases, due mainly to the emerging incidence of people whose disability manifests after the inception of the scheme.

Gross cost

A range of assumptions around service models and triangulations of data sources was used in developing the estimated gross costing of the scheme.

The assumed service model for a NDIS assumes a recognition of, and support for, current unmet and under-met need, and probable unsustainable burden on carers. At the same time, it acknowledges the need to achieve a balance between formal paid care and an infrastructure of informal care and community-based care (including workplace) options. Based on this service model, and assuming a target group aged less than 65 at onset of disability.²

- The ultimate annual cost of care and support was estimated at \$9.5 billion. These annual costs include all people aged less than 65 with pre-existing disability.
- The annual cost of equipment, aids and appliances was estimated at \$129 million.
- The annual cost of transport was estimated at \$90 million.
- The annual cost of home modifications was estimated at \$159 million.
- The following items of care and support were assumed to be met by other funding sources, and hence were not included in the costing of a NDIS. However, to the extent that demands on these services may be mitigated by a NDIS, it is argued that total government costs associated with a NDIS may be less than is directly apparent.
 - The annual cost of income support was assumed to be currently met by the Disability Support Pension (for people with disability) and by the Carers' Payment and Carers' Allowance (for carers of people with disability).

² More comprehensive costings, including if all ages at onset are covered including aged care, are included in the full report.

- The annual cost of homelessness (specifically the cost of housing) was also considered to be met through other government funding (primarily the SAAP scheme).
- The annual cost of hospital, medical, dental and pharmaceuticals used by people with a disability was assumed to be met by the health system (Medicare and other public and private funding arrangements).
- The annual cost of residential aged care was assumed to be met by the programs designed for this purpose.
- An administration fee of 10 per cent was included in the cost of a NDIS, giving a total ultimate gross annual pay-as-you-go cost of **\$10.8 billion**.

For catastrophic injury, the service model assumed continues the current indemnity-based and fully-funded approaches of Australian accident compensation schemes. Based on this model, the estimated gross annual fully-funded cost of lifetime care and support as a result of injury is \$1.4 billion on a prospective basis (that is, new injuries only). Existing and potential offsets are estimated at \$850 million.

Net cost and recommended funding option

Direct offsets to the NDIS gross annual payments are available through the National Disability Agreement (formerly CSTDA) and HACC programs, accident compensation schemes, community mental health programs, and a variety of aids and appliances and transport subsidy schemes. The estimated total annual direct offsets in current nominal values amount to **\$5.6 billion**.

Further indirect and future offsets have not been included in the nominal costing of the scheme, but there is a very strong argument that a NDIS would prove net-cost beneficial over a reasonably short time horizon (perhaps 10 years after introduction).

A range of funding options was considered for a NDIS. Compared to the existing pay-as-you-go system of welfare programs, it was seen as desirable to introduce some of the discipline and longer-term stability of the funded compensation systems. At the same time, it was seen as important to include people with pre-existing disability (that is, not just new incidences of disability). On costing, the resulting Scheme (of new incidences of disability and pre-existing disability) on a fully-funded basis was seen to be both beyond an affordable level of acceptability at the present time (as discussed with the DIG), and also probably not necessary to achieve the objectives of the Scheme.

Accordingly, the preferred funding option is one which assumes:

- a coordinated service model providing care and support including respite, accommodation support, aids and equipment, transport assistance, and a range of community and day programs;

- a cost model commitment based on the notion of “reasonable need” for services, as derived above;
- 30 per cent funding of new incidence from scheme commencement and future years for under 65 year olds who sustain a new disability, and ongoing annual pay-as-you-go funding of under 65 year olds with an existing disability from scheme commencement. 100 per cent fully-funding new incidence is costly in cash flow terms; hence, the 30 per cent funding of new incidence was considered an appropriate level of pre-funding as several years of cash flows are set aside upfront to allow for adequate life planning; and
- benefits for these eligible people to be available for life.

This option is considered to provide the following advantages and benefits:

- it recognises the current unmet and under-met need for care and support and unsustainable burden on carers, while at the same time keeping the system viable and engaging in a partnership between funded support, informal support, and community based activity and infrastructure;
- it achieves equity between people with existing severe or profound disability, and those who acquire them in the future;
- it recognises the limits of a disability system in seeking to offer a suite of programs and support for people whose disability emerges before age 65, with the aged care system retaining responsibility for those who acquire a disability after age 65; and
- it captures the benefits of the prudential insurance model of accountability, funding stability and transparency, while at the same time being affordable and achieving the other benefits.

Including administration expenses, this approach would require annual gross funding beginning at **\$12.5 billion if begun in 2009 (existing prevalence funded annually and new incidence partially (30 per cent) funded).**

Further indirect offsets will emerge in the following areas from an effective NDIS:

- anticipation of the inevitable escalation in disability and care and support costs, so that the true net cost of a NDIS is projected to be about \$2 billion per annum;
- future savings of \$2 billion per annum in income support payments;
- significant (50 per cent over time) easing in the massive increasing burden in aged care;
- major contribution to the community management of chronic and complex diseases, supporting the increasing cost of the health system; and
- providing better options and reducing costs (illustratively by \$200 million per annum) for prisons and psychiatric hospitals.

Therefore in considering a funding model for implementation of the Scheme, the following considerations are relevant.

- Current disability system expenditure represents about 1 per cent of taxable income, and already has a major workforce shortage. Pumping a more than 100 per cent increase into the system would achieve little short term in creating a workforce, but would almost certainly be inflationary in the cost of support. Even with the injection of funding recommended below, a strong workforce strategy will be required.
- The nature of disability services, and particularly the expectation (or lack thereof) of available services will take some time to re-engineer into a cooperative management system focussing on outcomes, with an active eligibility function. In other words, take-up and implementation of the new system will be slow and the ultimate level of take-up is very uncertain.
- Moreover, it is likely that a significant proportion of the conditions included in the NDIS costing will be found to be more appropriately managed under a health/medical paradigm, which will further reduce the ultimate cost. Views on the exact implications of this sensitivity differ widely, and hence some simple testing of options is presented in this report.
- Even in the absence of direct transfer of cost responsibility from a NDIS to other responsible agencies, the implementation of a NDIS is expected to generate significant efficiency benefits for a range of government programs.
- Consequently, the actual utilisation and ultimate cost of a NDIS is somewhat speculative, and will certainly be different from the “need” projections in this report. Only time will tell how the dynamics of the system will emerge, but evidence from innovative systems in both accident compensation (for example, Lifetime Care and Support) and the health system (for example, the Enhanced Primary Care packages) demonstrate slow initial take-up.

Considering these arguments, the current level of unmet need, and the assessment in this report that the current system will need to increase annually by 5 per cent to 10 per cent in real terms simply to maintain its current “crisis management”, it is suggested that annual disability funding be increased within a NDIS model by 30 per cent initially in real terms (in two tranches of 15 per cent), then incrementally by up to 10 per cent per annum in real terms while the NDIS is developed, workforce is recruited, and system dynamics emerge. Reassessment should take place annually to report on the emerging dynamics, trends, assets and liabilities of the system.

Table 1 provides an illustrative implementation projection based on this recommendation. It would require an initial additional funding requirement for a NDIS of **\$0.97 billion** in the projected start year of 2011 (to \$7.44 billion in total), and **\$2.04 billion** in 2012, with gross funding increasing by up to 10 per cent per annum in real terms until the projected ultimate gross target is attained—say in 2020 at **\$14.59 billion**. This ultimate target requires an additional **\$4.56 billion** per annum over projected disability funding growth to 2020 including \$2.28 billion in pre-funding for insurance reserves.

Table 1 NDIS Funding Requirement

Current programs (\$b)			NDIS			NDIS Net cost components (e)		Growth funding needed (\$b)		
Year	Total (a)	Under 65 (b)	Target group (c)	Net annual cost (d)	Net annual cost (d)	Enhanced services (e)	New incidence funding (e)	Current (f)	NDIS (f)	Extra growth (f)
2008	7.95	5.59	\$b	\$b	% taxable income					
2009	8.35	5.87								
2010	8.76	6.16								
2011	9.20	6.47	7.44	0.97	0.17%	0.97		0.31	1.28	0.97
2012	9.66	6.79	8.83	2.04	0.35%	2.04		0.32	1.39	1.07
2013	10.15	7.13	9.55	2.42	0.41%	2.14	0.28	0.34	0.72	0.38
2014	10.65	7.49	10.27	2.78	0.47%	2.25	0.54	0.36	0.72	0.36
2015	11.19	7.87	10.99	3.13	0.53%	2.36	0.77	0.37	0.72	0.35
2016	11.75	8.26	11.71	3.45	0.58%	2.42	1.04	0.39	0.72	0.33
2017	12.33	8.67	12.43	3.76	0.63%	2.37	1.39	0.41	0.72	0.31
2018	12.95	9.11	13.15	4.05	0.68%	2.23	1.82	0.43	0.72	0.29
2019	13.60	9.56	13.87	4.31	0.72%	2.16	2.16	0.46	0.72	0.26
2020	14.28	10.04	14.59	4.56	0.75%	2.28	2.28	0.48	0.72	0.24

Notes: (a) Projected funding required for community care and support, assuming real growth of 5% per annum up to 2020.
(b) Projected funding required for community care and support for people aged under 65, assuming real growth of 5% per annum up to 2020.
(c) Projected funding required for NDIS Option 6, assuming implementation of 15% additional growth above current funding projections in (b) for years 2011 and 2012 (ie 7.44 = 6.47 x 1.15), then linear additional annual growth to reach the NDIS Target amount by 2020.
(d) Additional growth funding by year to achieve plan (c), both in \$billions and % taxable income.
(e) Components of additional growth funding – assumed to provide enhanced services until estimated need is met (in 2016), then phased in to achieve 50:50 between enhanced services and advance funding.
(f) Growth funding required by year for current system funding projections versus NDIS.

The ultimate net additional annual cost of a NDIS in terms of enhanced service cost would therefore be approximately **\$2 billion to \$2.5 billion** (about **0.4 per cent of taxable income**, or 0.2 per cent of GDP), with an additional \$2 billion to \$2.5 billion being set aside as reserves.

There is a strong argument that this net cost will be more than offset over time by the indirect cost savings presented above.

Implementation

The range of issues to be considered in fulfilling the possibilities of this report is extremely wide, and it is beyond the scope of the present report to fully develop an implementation plan. However, it is proposed that implementation needs to be addressed within the five main “issue areas” of:

- 1 Commitment – Stakeholder Consultation and Management
 - (a) Clearly the threshold implementation requirement for a major change such as a NDIS is a commitment from government at all levels that the proposal represents a strong piece of economic and social policy reform—indeed a necessary piece of reform. This commitment was indicated in a preliminary stage at the *Australia 2020 Summit*, and it is hoped that the present report is able to inform the future debate in a more concrete fashion.
 - (b) Once central government is committed to the process a major engagement process will be required to involve and both educate and learn from a wide range of stakeholders—to educate and communicate the concept and potential of the vision, and to learn about the many operational and real life situations which will need to be accommodated.

- 2 Governance – Building the Infrastructure

Outside of the political and stakeholder management issue, there will be an important process of envisaging and implementing what the new system would look like—policy, bureaucracy, fund-holding, IT and administration, accountability, reporting and best practice research.

Some structural options are proposed in the report, that concern a central conceptual vision with a core of positive outcomes for people with disability.

Within the wider governance debate, subsidiary issues will require resolution around the three operational streams of insurance, scheme coverage and entry points, and service delivery.

- 3 Insurance – Insurance Management

Due to the nature of available data, there is considerable uncertainty in this report. Leading up to scheme start-up, the numbers will need to be tested and revisited from all angles and involving collaboration with government and the emerging governance and infrastructure model. Ideally, an evaluation would start to capitalise on what data already exists to begin the process of longitudinal management of information.

Similarly, the whole process of levy implementation, notification and collection will require a major collaborative engagement with other government agencies, as will the processes of funding, investments, disbursements and payment options and their links with a centralised IT system.

Finally, the processes around prudential and outcome governance within an insurance framework will need to be designed and built into a risk management and reporting system.

4 Coverage and Eligibility – Assessment/Review

Parallel with developing a vision of a system and its funding and reporting flows, the implementation plan must build a process of identifying, assessing and accepting where appropriate entrants to the system. It must also be able to conduct an assessment of reasonable needs and build a support and case management plan on an individual basis, and implement service delivery.

To a large extent, similar pieces of work have commenced in individual jurisdictions, but in a disjointed and inconsistent manner. It will be a major implementation requirement—but also a challenge—to reach agreement on a way forward.

5 Service (Care and Support) Delivery – Care and Support Management

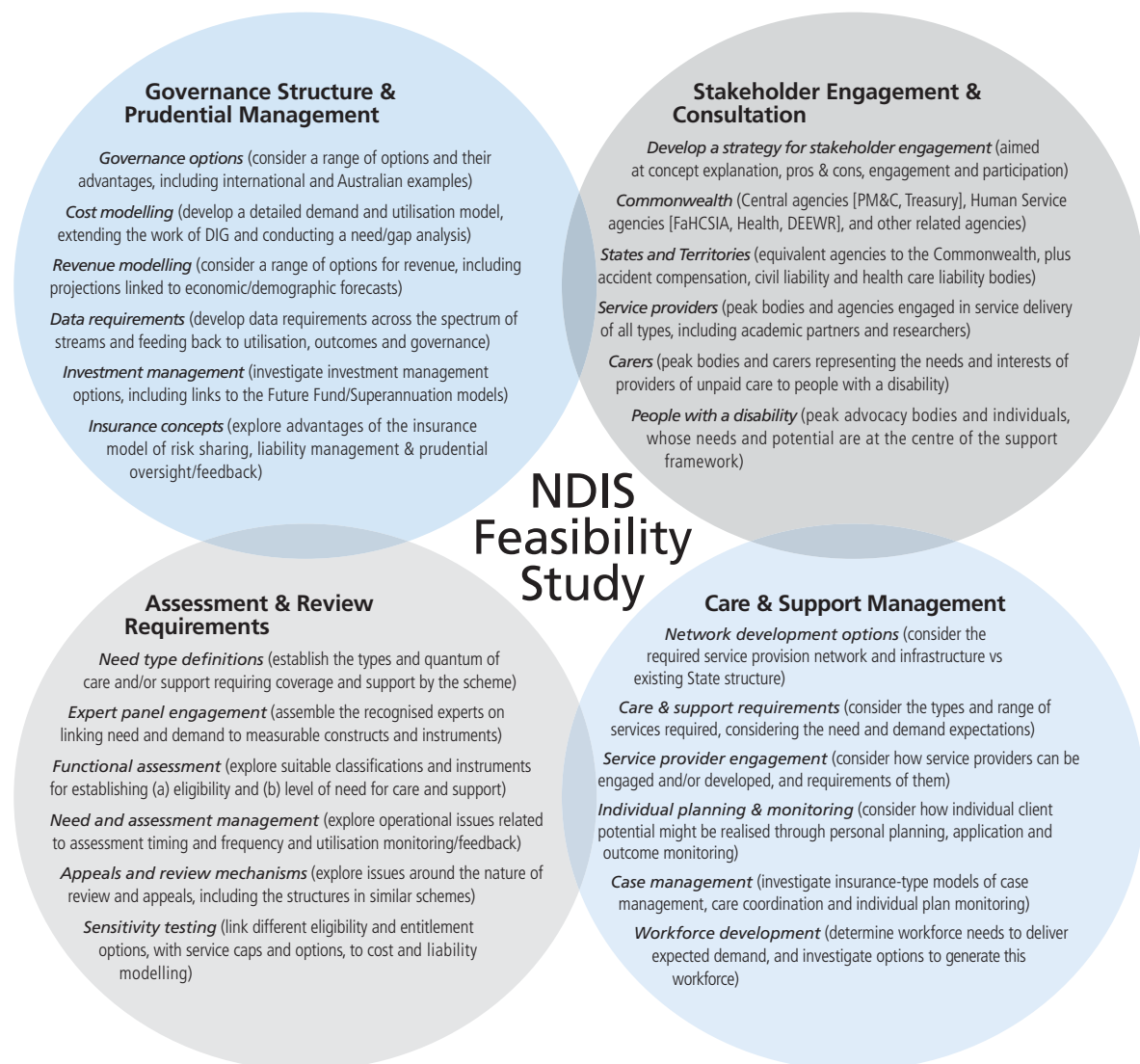
Finally, at the core of the development of the care and support delivery framework will be the extremely problematical implementation requirement of how to build a workforce and/or alternative capacity to accommodate the burgeoning support needs.

This supply issue, and how the field staff and service providers interact with the insurance and administrative infrastructure, will be critical in achieving the desired outcomes of the proposal.

With respect to the activation of this implementation plan, our understanding is that the DIG may recommend a detailed and immediate feasibility study around a NDIS.

Figure 1 presents a schematic view of what such a study might consider, bringing out the ideas and themes expressed in this section.

Figure 1 NDIS Feasibility Study



Appendix D

Insurance Scheme Funding Arrangements

In an Australian insurance³ context, it is a requirement for operations to be structured on a fully-funded basis, plus a margin to increase the probability of sufficiency. This means that each year the premiums that are collected are set aside and invested to meet the full cost of claims incurred or received in the year underwritten by the policy,⁴ and also to provide a 'risk margin' to cover the uncertainty inherent in the claims process.

It is usual practice for State and Territory accident compensation schemes, which are not required to report to APRA, to fund their operations in a similar manner. The NSW Lifetime Care Authority, which is the only Australian scheme specifically established to provide for the lifetime care and support needs of a group of people (in this case those injured in NSW in a motor vehicle injury), is also funded in this way.

In these operations, therefore, the premiums are based on a number of critical assumptions including the expected number of claims and the forecast cost of those claims. Then the scheme managers have to balance the assets of the scheme against the liabilities to ensure that funding is available to meet future costs.

Fully-funded schemes are attractive from an intergenerational perspective, because future tax payers do not have to meet costs that were incurred in earlier years. Such intergenerational neutrality is particularly important when there are likely to be significant demographic shifts, such as the current expectation that as the Australian population ages, people with disability are likely to increasingly outlive their parents.

In the short-term pay-as-you-go funding arrangements are cheaper than fully-funded models, but in the long-term fully-funded models are less expensive as the accumulated assets, and the investment return on them, become an ever increasing source of funds.

In Australia today, there are a large number of people with disability, whose needs are being met by their families and for whom no funds have been set aside to provide for their future care. In addition, many people with disability today have unmet needs for care and support, equipment, therapy and other services. As noted in this Report these costs are growing at around 4.8 per cent in real terms, and they represent a very significant notional unfunded liability.

The DIG in framing its recommendations therefore had to balance a preference for a fully-funded scheme, that would be a best practice insurance structure, a desire to meet current and future demands for services, the short-to medium-term fiscal

³ Insurance operations regulated by the Australian Prudential Regulatory Authority (APRA).

⁴ Policies may specify "claims incurred" or "claims made" coverage, which defines which events are eligible for coverage in a particular policy period.

outlook, the Government's commitment to fiscal restraint and the demographic and social forces that are causing an inexorable growth in the unfunded real costs of disability at rates that are well in excess of real GDP growth.

As a pragmatic way forward the DIG, after consulting with PwC, is recommending that the funding arrangements for a NDIS should include the funding to meet immediate demands for services on a pay-as-you-go basis for people with disability at the time the scheme is introduced and funding to meet both the immediate and some of the future costs of care and support for people who acquire or are born with disability after the scheme is introduced.

In the analysis undertaken for DIG by PwC, 30 per cent of the future costs of care of new incidence of disability is set aside each year. This will result in a growing asset pool as the funds are invested and should be sufficient to ensure that the scheme is managed based on insurance principles.

Over time more and more people will have 30 per cent of their future costs of care set aside. This will provide an offset to the demographic forces that would otherwise result in disability costs rising relative to GDP. Based on the calculations by PwC it seems reasonable to expect that while the introduction of a NDIS would lead to an increase in gross disability expenditure in the first few years of the scheme, thereafter gross disability expenditures would quickly stabilise relative to GDP, implying intergenerational neutrality.

In addition there will be potentially large savings in other government expenditures, including reduced dependence on the Disability Support Pension and Carer Payment and additional offsets in the health, criminal justice, aged care and other parts of the social service system as a result of the introduction of a NDIS.

Full details of the funding assumptions are available in the PwC Report.

Appendix E

Report of Disability Investment Group Consultations, 2008

The Disability Investment Group received information, advice and ideas on a range of topics from people with disability, their families and carers, and organisations involved in the disability sector. This prompted and informed a series of consultations which were held in Brisbane (27 October 2008), Sydney (29 October 2008), Perth (31 October 2008) and Melbourne (10 November 2008).

Consultations

The overwhelming message from the consultations was that individuals and families are not looking for handouts from the Government, but the removal of bureaucratic barriers that prevent them from accessing the services and assistance they need to be able to support themselves or a family member.

Key themes emerging from the consultation sessions included:

1. challenge of securing permanent accommodation for people with disability, which reflects their changing needs across the life course;
2. levers, such as tax incentives, which the Commonwealth Government could utilise to support and encourage investment in accommodation for people with disability and the private funding of aids and equipment;
3. strategies to increase employment opportunities for people with disability and the importance of leadership, especially from the Commonwealth Government, in this area;
4. importance of diversity and flexibility in disability services delivery;
5. individual's experiences with Special Disability Trusts and the need for the Commonwealth Government to endorse and take action on the Senate Committee's Inquiry into Special Disability Trusts Report and recommendations;
6. high and ongoing cost of home modifications and aids and equipment;
7. importance of individualised support packages and barriers to the utilisation of these packages; and
8. challenges experienced by individuals in relation to various Government disability employment services and support programs.

A list of those who attended the consultations and the key issues raised at each follows.

Brisbane Consultation - 27 October 2008

Participant List	Representing
Mr Geoff McKeich	Hope Australia - <i>a not-for-profit organisation which has been established to provide home ownership to people with severe to profound intellectual disability.</i>
Ms Diane McKeich	
Dr Alex Dowland	
Mr Ian O'Malley	Foresters Community Finance - <i>a community finance institution providing community finance, social investment and education for the third and fourth sectors.</i>
Dr Ben Lawson	Individual
Dr Amanda Mergler	Individual
Mr Jim Mergler	Individual

Key issues raised

1. The implications, for people with mild disability, of limited State and Territory Government disability funding and the prioritisation of people with complex needs and challenging behaviour.
2. The importance of standardised data, across all jurisdictions, to enable accurate measurement of unmet need and the development of appropriate strategies to address the existing, future and unmet needs of people with disability.
3. The compartmentalised nature of existing disability support and how it hinders the implementation of a holistic model, integrating housing and support services, providing individualised support packages.
4. The need to extend access to the First Home Owners Grant to trusts for people with disability (in line with Recommendation 8 of the Senate Committee's inquiry into Special Disability Trusts).
5. The need for incentives, namely tax credits/deductions, to encourage and support organisations investing in accommodation projects for people with disability.
6. The difficulties experienced by individuals seeking to transfer their support packages between jurisdictions and how this hampers their ability to gain and sustain employment.
7. The importance of individualised support packages and how the potential loss of this support acts as a disincentive for some people to move from the Disability Support Pension to employment.
8. The significance of diversity in the provision of support services and accommodation.
9. The importance of flexibility in service delivery and the apparent lack of it in the delivery of services provided by 'mega service providers'.

Sydney Consultation - 29 October 2008

Participant List	Representing
Ms Fiona Anderson	Association for Children with Disability NSW - <i>provides information and support to parents and families who have a child or young adult with any type of disability or developmental delay across NSW.</i>
Ms Mary-Lou Carter	
Mrs Margaret Colebrook	Let us Hear - <i>represents deaf and hearing impaired people between the ages of 21 and 65 years.</i>
Ms Belinda Epstein-Frisch	Family Advocacy - <i>assists families build capacity to self advocate, develop leaderships and provide information about disability matters.</i>
Ms Rebecca Fletcher	Lorna Hodgkinson Sunshine Home - <i>provides accommodation, community access and employment programs.</i>
Mr John Jensen	House with No Steps - <i>provides accommodation, respite care, employment and community programs.</i>
Mr Patrick Maher	National Disability Services - <i>an industry association representing over 600 disability service providers.</i>
Mr Simon Schwab	Individual

Key issues raised

1. The cost of hearing aids to persons aged over 21 years, who are not in possession of specific concession cards, due to the lack of entitlement to subsidised aids, and the isolation and vulnerability experienced by those unable to afford the high cost.
2. The need for the inclusion of accessibility standards, based on the Principles of Universal Design, in the national building code.
3. The high cost of home modifications and the negative impact such modifications can have on the value of the house. The high cost of modification is particularly problematic in rental accommodation.
4. The importance of aids and equipment in enabling people with disability to achieve their potential and the proposal that tax credits/deductions be provided on the cost of privately-funded aids and equipment.
5. The need for leadership, from the Commonwealth Government, in the area of the employment of people with disability.
6. The proposal that Governments should consider policies that support preferred procurement through organisations employing people with disability.
7. The barriers faced by individuals seeking to transition from the Business Services program (FaHCSIA) to the Disability Employment Services (DEEWR).

Perth Consultation - 31 October 2008

Participant List	Representing
Ms Phyllis Breheny	Individual
Mr Brian O'Hart	Individual
Mr Ray Walter	Individual
Mr Harry Weir	Planned Individual Networks - <i>a not-for-profit organisation created by families to support families plan and create a secure future for their relative with a disability.</i>

Key issues raised

1. The need for the Commonwealth Government to endorse and take action on the Senate Committee's Report and recommendations on Special Disability Trusts (SDT).
2. The lack of endorsement of SDTs by professional bodies/organisations such as public trustees and lawyers.
3. The proposal that beneficiaries be able to contribute to their own trusts.

Melbourne Consultation - 10 November 2008

Participant List	Representing
Mr Brian Broughton	Individual
Mr Stephen Gianni	Leadership Plus - <i>community organisation that promotes people with disabilities as leaders in the community.</i>
Ms Lyla O'Hara (via telecon)	Individual

Key issues raised

1. The inability to have more than one beneficiary for a SDT and the proposal that this needs to be changed as often families have more than one dependent with a disability.
2. The need to balance the streamlined development of housing for people with disability, without reducing opportunities for social entrepreneurial activities by families, community and church groups.
3. The importance of developing leadership capacities of people with disability to enhance employment opportunities.
4. The need to encourage the employment of people with disability and the proposal that this be done through the introduction of levies upon companies that do not meet a specific threshold. Funds collected would be redirected towards funding workplace modifications to support the employment of people with disability.
5. The limitations of Medicare coverage for people with disability.

Correspondence

Key themes emerging from the submissions and correspondence sent to the Disability Investment Group (DIG) included:

1. difficulties with and improvements for SDTs;
2. concern about the unmet need for accommodation and support services and options to ensure secure housing for life;
3. strategies to encouraging private investment and innovation and community financing;
4. proposals for establishing disability trusts for developing capacity and advocacy;
5. identification of barriers to meaningful community participation by people with disability;
6. strategies for encouraging mainstream employment of people with disability;
7. need for a common insurance scheme;
8. need to engage corporations in the work of disability-based charities;
9. concern about unmet need for access to early intervention across all disability support and services;
10. ideas to build the leadership capacity of people with disability; and
11. need for greater disability research and data.

Note: The views and opinions recorded in this paper are those expressed by individuals and representatives of a range of organisations who engaged with the DIG. They do not necessarily reflect those of the DIG or of the Department of Families, Housing, Community Services and Indigenous Affairs.

Appendix F

Recommendations of the Senate Standing Committee on Community Affairs 2008, *Building trust: Supporting families through Disability Trusts*, October

Recommendation 1

The committee recommends that the special disability trust eligibility requirements in section 1209M of the *Social Security Act 1991* be amended to:

- remove section 1209M(b);
- include eligibility requirements which effectively enable those with intellectual disabilities or mental illnesses to become beneficiaries of special disability trusts.

Recommendation 2

The committee recommends that the asset value limit for special disability trusts in section 1209Y of the *Social Security Act 1991* be increased to \$1,000,000 and annually indexed according to a rate which reflects ordinary investment returns or the Consumer Price Index whichever is greater.

Recommendation 3

The committee recommends that the provisions relating to the special disability trust gifting concession be amended to annually index the gifting concession limit to the rate applied to the special disability trust asset value limit.

Recommendation 4

The committee recommends that, if after the adoption of the recommendations in this report there is no improvement in the uptake of special disability trusts after two years, options to expand eligibility for the gifting concession should be reviewed.

Recommendation 5

The committee recommends that the tax arrangements applying to SDTs be changed so that:

- the sale of a property that is owned by a special disability trust and used by the beneficiary as their principal place of residence be treated the same as any other person's principal place of residence, that is, exempt of capital gains tax;
- the transfer of property and other assets to a special disability trust is exempt from capital gains tax and stamp duty;
- unexpended special disability trust income is taxed at the beneficiary's personal income tax rate.

Recommendation 6

The committee recommends that the allowable uses of special disability trusts be expanded to include all day-to-day living expenses that are met to maximise the beneficiary's health, wellbeing, recreation and independence.

Recommendation 7

The committee recommends that unexpended income from a special disability trust be able to be contributed, on a pre-tax basis, to a superannuation fund for the trust beneficiary.

Recommendation 8

The committee recommends that when a special disability trust is used to purchase a first home for the trust beneficiary, the First Home Owner Grant should apply and be payable to the trust.

Recommendation 9

The committee recommends that the government review appropriate options to provide additional assistance to families establishing and maintaining a special disability trust including low cost legal and financial advice, as well as funding for the development of long-term planning.

Recommendation 10

The committee recommends that requests for audits of a special disability trust be restricted to one external audit per financial year, unless the Secretary of the Department of Families, Housing, Community Services and Indigenous Affairs determines this restriction should be waived.

Recommendation 11

That the single trust rule in section 1209M(6) of the *Social Security Act 1991* be amended to allow two trusts for each beneficiary.

Recommendation 12

The committee recommends that Centrelink be designated as the agency responsible and accountable for ensuring that special disability trusts are promoted and understood among families caring for members with disability.

Recommendation 13

The committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs in partnership with industry bodies and peak carer organisations develop a training package for financial and legal advisers focussed on future planning for carers of people with disability, including special disability trusts.

Recommendation 14

The committee recommends that the government consider changing the name of special disability trusts, for example to disability support trusts.

Appendix G

Australian Institute of Health and Welfare 2008, *Scan of disability databases in the non-government sector, December*

Summary

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) engaged the Australian Institute of Health and Welfare (AIHW) to carry out a scan for disability-related data holdings in the non-government sector—private sector and non-profit organisations—on behalf of the Disability Investment Group (DIG). The scan was undertaken in late October and November 2008.

Using agreed key words for online searching the scan revealed a substantial number of government-funded disability databases or databases with disability-related data items, managed by government. A relatively low number of private sector data holdings were located: 23 substantive holdings of person-level data and an additional 4 holdings of data about disability goods and services, described in the following pages. This confirms the findings of another search for disability resources by the University of New South Wales (Edwards & Fisher 2008). A large number of service directories (lists of disability support agencies and addresses) were also located but were considered out of scope.

The nature of data items contained in the various databases is diverse and the level of formal and accessible documentation ranges from scant to good. The general lack of comprehensive metadata and documentation hampered the assessment of data comparability. Most databases appear to contain standard demographic data items but there is considerable variation in disability measures and related data items. Data comparability problems, patient/client consent issues, and a general lack of good quality documentation are likely to pose obstacles to use of these databases for other than their intended purposes.

Table 1 lists the databases for which more detailed information was sought and received and the type of information that was made available to the AIHW. An 'X' indicates that the information was not provided and could not be located online.

Table 1: Database comparability chart

	Publicly available data quality information	Number of records	Co-morbidity data	Listed data items	Funding information	Appropriate collection years	National data
Multiple Sclerosis Databases	✗	✓	✗	✓	✓	✓	✗
National Joint Replacement Registry	✓	✓	✗	✓	✓	✓	✓
IDEAS Disability Info Line Service User Records	✗	✓	✗	✓	✓	✓	✗
Intellectual Disability Exploring Answers (IDEA) Database–WA	✗	✓	✓	✓	✓	✓	✗
Australian Cerebral Palsy Register	✗	✓	✓	✓	✓	✓	✓
The Spastic Centre Client Database	✗	✓	✓	✓	✓	✓	✗
WA Register for Autism Spectrum Disorders	✗	✓	✓	✓	✓	✓	✗
Motor Neurone Disease Database	✗	✓	✗	✓	✓	✓	✗
Australian Motor Neurone Disease Registry	✗	✓	✓	✓	✓	✓	✓
Australian Twin Registry	✗	✓	✗	✗	✓	✓	✓
National Trauma Registry Consortium (Australia & New Zealand)	✗	✓	✗	✓	✓	✓	✓
Australian Cystic Fibrosis Data Registry	✓	✓	✓	✓	✓	✓	✓
Australian Longitudinal Study on Women's Health: Older Cohort, Wave 4, 2005	✓	✓	✓	✓	✓	✓	✓
Patients of NSW Developmental Disability Health Unit	✗	✓	✓	✓	✓	✓	✗
I-CAN Instrument for the Assessment and Classification of Support Needs	✗	✓	✓	✓	✓	✓	✗
Epilepsy Action, Australia	✗	✓	✗	✓	✓	✓	✓
Tasmania Epilepsy Register	✗	✓	✓	✓	✓		✗
Australian Rheumatology Association Database	✗	✓	✗	✗	✓	✓	✓
Australian Rehabilitation Outcomes Registry	✗	✓	✓	✓	✓	✓	✓
National Genetic Heart Disease Registry	✗	✓	✗	✓	✓	✓	✗
Australian Spinal Cord Injury Register	✓	✓	✗	✓	✓	✓	✗
Victorian State Trauma Registry	✗	✓	✓	✓	✓	✓	✗
Victorian Orthopaedic Trauma Outcomes Registry	✗	✓	✓	✓	✓	✓	✗

Project aim

To identify non-government disability databases in Australia, including information on database scope, content and data comparability.

Methods

The scan for disability databases relied primarily on internet searching, using criteria agreed between AIHW, FaHCSIA and the DIG and direct approach to peak bodies, research and other organisations.

In the initial phase an online keyword search was used to locate organisations with disability data holdings. Around 50 organisations were identified as potential data owners/custodians. These organisations plus 15 member organisations on the AIHW Advisory Committee on Functioning and Disability Data (ACFADD) were contacted by letter to ascertain any data holdings and seek referral to other potential data owners. Responses varied from vague to highly informative.

Following the mail-out, an online search was used to locate readily accessible information on disability databases and annual reports containing disability data.

A second phase involved follow-up communication to obtain further detailed information. Around 30 potentially relevant databases were identified through this process; for various reasons some databases are not included in this report, for example, a lack of sufficiently detailed information or because they were deemed not sufficiently relevant.

Findings

The project encountered difficulty in obtaining detailed information on some databases, which may have limited the number of existing databases that could be relevant. The overall picture is one of very limited publicly available (or any) metadata about data holdings, leaving personal contact as the only way to obtain detailed information.

Not all data owners/custodians were willing to share information about their databases. While some organisations returned multiple responses for requests for information about known databases, some did not respond at all and others said they would respond but did not. Due to the nature of the request of information, which was in part the identification of other organisations' databases, the snowball effect of information gathering was somewhat restricted by the need to complete the scan in November 2008.

Online searching for disability databases highlighted several issues. Firstly, the majority of databases on disability and community services are government-owned or sponsored. Key words and phrases to identify databases and registers returned far more links to government sites and organisations than for non-government organisations.

Many of the non-government organisations with data holdings stated that they receive government funding for data collection, for example, through an educational or research grant. Other non-government organisations use charitable donations to fund data holdings, or do not collect data due to lack of funding for ongoing maintenance. As many of these organisations rely on philanthropy, the cost of maintaining a database or register could divert financial and human resources away from service delivery into administration. This appears to be a main reason for the predominance of government-funded disability databases.

Secondly, few non-government organisations have database or registry information that is readily available for online use. The accessible sites tend to have registration pages and contact information for people who would like to join a register. Any metadata that might exist does not seem to be available for public viewing, at least not through online searching. Data holdings are similarly not publicly available in de-identified form such as online data cubes. Data may be provided by some organisations upon request, though this was not explored.

Some organisations provide summary information about their databases in annual reports. These summaries tend to be brief and contain little if any information about data quality. The Cystic Fibrosis Data Registry is an example of publicly available information management policy, a rare exception in the field of non-government disability data.

Most organisations collect and hold data for their own purposes, such as keeping account of the client base. Therefore, as long as they are able to obtain the information they need to operate effectively, data quality statements would not appear to be an issue in the operational sense. Many disability data registers operate through a person registering their interest, online or via telephone, with an organisation in order to receive information or practical support. A person from the organisation then contacts the person and enters all required information into the database. Data quality control is essentially monitored at the point of data entry.

Further information on the databases is available on request.

Data comparability

Many of the databases contain similar types of information, such as patient/client demographic data, specific types of disability, and treatment outcomes. While there is some commonality across databases, at a detailed level the data holdings are in fact quite diverse. For example, many collect name, sex, and date of birth though some choose not to include name and record age instead of date of birth. In general though, the demographic data items appear to be similar across the board.

The comparability of data depends on the purpose or intent of the database, and many organisations appear to collect information for their own purposes: to facilitate improved service provision; to estimate prevalence of certain disabilities; to monitor

and report on the experiences of people with a specific disability; or to generate a database of information in order to conduct research to advance knowledge about a type of disability.

In some cases, organisations collect their own data in addition to elements defined for the Commonwealth State Territory Disability Agreement (CSTDA) National Minimum Data Set (NMDS). The CSTDA information is already reported by government, and the remaining data need only suit the organisation's own information needs. In this respect, much of the information about specific disabilities and diseases is not comparable.

A few databases included in the report are not disability databases as such but are more accurately described as injury and rehabilitation databases. These databases could be useful in terms of disability incidence and disability-related functional outcomes.

In terms of collection periods for the data, most databases have existed since 2005 or earlier, though some were more recently established. Almost all are ongoing collections or were established with that intention. Geographic coverage is somewhat varied; around half of the reported databases operate at a national level and the other half collect data on individual states/territories or regions.

Other relevant research

The Social Policy Research Centre (SPRC) at the University of New South Wales published a report in September 2008 titled '*Disability Policy – Sources for Evidence*'. The SPRC report examines disability policy development in New South Wales and provides key information in both government and non-government sectors on journals, publications, academic bodies conducting research, data sources, and listings of peak bodies and government disability agencies (current as at June 2008). Section 5 contains information about data sources in New South Wales, noting AIHW, the Australian Bureau of Statistics (ABS) and the CSTDA NMDS as three main sources of disability data.

The SPRC survey of information sources covered both government and non-government data and information. However, only government collections were identified as having 'core' information on disability. Though quite brief and with a focus mainly on New South Wales, the SPRC report is recommended for consideration by the DIG.

Reference and contact details for the SPRC report are as follows.

Contacts

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Email: karen.fisher@unsw.edu.au, robyn.edwards@unsw.edu.au;

Fax: 61-2-9385 7838

Reference

Edwards R. & Fisher KR. (2008), *Disability Policy – Sources for Evidence*, SPRC Report 15/08, Social Policy Research Centre, University of New South Wales, Sydney.

Report URL

http://www.sprc.unsw.edu.au/reports/2008/Disability_Policy.pdf

Appendix H

Letter from Chairman, Disability Investment Group to the Department of Families, Housing, Community Services and Indigenous Affairs in response to the *National Rental Affordability Scheme - Technical discussion paper, 29 May 2008*

29 May, 2008

Section Manager
National Rental Affordability Scheme
Department of Families, Housing, Community Services and Indigenous Affairs
PO Box 7576
Canberra Business Centre ACT 2610

Dear Sir/Madam

I refer to the *National Rental Affordability Scheme - technical discussion paper*, which seeks comments from interested parties by 31 May 2008.

I am writing on behalf of the Disability Investment Group (DIG) which was established by the Parliamentary Secretary for Disabilities and Children's Services, the Hon Bill Shorten MP, on 23 April, 2008.

The Group's Terms of Reference include a requirement to "explore government assistance to encourage family and private investment in the provision of housing ... for people with disability".

In addressing its Terms of Reference, the DIG is seeking to leverage other Government policy initiatives as much as possible, so that they meet the needs of people with disabilities.

DIG therefore welcomes the announcement of the National Rental Affordability Scheme with its intention to expand institutional investment in new affordable rental housing, including people with disabilities.

Access to secure, suitable housing is not just a basic human need, but is central to a person's participation in the community, whether through social connection and engagement, employment or personal well-being.

People with disabilities are around three times more likely to occupy public housing than are people without a disability. According to the Australian Institute of Health and Welfare the proportion of public housing occupied by people with disabilities in Victoria had risen from just over 20 per cent in 2001-02 to almost 40 per cent in 2005-06. There is little to suggest that this pattern would be significantly different in other jurisdictions.

It is therefore a matter of some concern then, that over the same period, the supply of public housing has decreased across Australia and so the DIG strongly welcomes the proposal to establish a NRAS.

However it also strongly believes that the proposed Scheme needs to be modified in three critical areas to ensure that people with disabilities are not excluded from those that will be supported by NRAS.

1. Level and Structure of Incentives

DIG believes that with the proposed level of NRAS subsidy it will be only marginally viable for private sector investors to participate in the Scheme.

Given the additional costs experienced both in the establishment of disability accessible or adaptable accommodation and the higher ongoing costs of managing tenancies involving people with disability or mental illness, DIG is concerned that applying the standard level of incentive to housing for people with disability or mental illness will not attract any additional investment into appropriate housing for these clients.

Therefore, DIG expects that NRAS as currently designed would have the, presumably unintended, consequence of depriving disabled people from sharing in the benefits available under the Scheme. Consistent with the Government's social policy objective of improving the housing and other circumstances of people with disabilities it is important that the Scheme be modified to reflect the higher costs of housing people with disabilities.

If this does not occur NRAS will in effect discriminate against people with disabilities because investors and providers of housing will make the "rational" economic decision not to invest in housing for those with disabilities because their economic return will be lower.

DIG therefore recommends that the Scheme should be amended by increasing the payment made in relation to housing for people with disabilities to recognise the higher costs of providing and servicing their housing.

The additional subsidy could be structured in different ways and in the short time since the Technical Discussion Paper was issued DIG has not been able to undertake this analysis. One approach would be to set an additional level of subsidy in return for a

guaranteed minimum number of people with disabilities to be housed on a project by project basis.

In order to ascertain the required subsidy, DIG also recommends that some detailed modelling be undertaken on both the level and structure of the subsidy and DIG would like to work closely with you on the development of further financial models, to ensure that housing for people with disabilities moves from the margin to the mainstream.

DIG would also draw attention to the broader cost to government of failure to provide sufficient suitable and affordable accommodation to people with disability or mental illness. It is widely acknowledged that once people with disability or mental illness become disengaged from secure housing, their risks of requiring higher intensity levels of government assistance (including acute health interventions and imprisonment) increase significantly.

Therefore, while the recommendation from DIG to increase the NRAS subsidy for people with a disability will add to the costs of the Scheme, it will certainly reduce government outlays in other areas.

2. Adaptable and Accessible Housing Standards

DIG notes the target of 50,000 affordable rental dwellings by 2012 and short timetable for expressions of interest and lodgement of tenders.

There is therefore likely to be a trade-off in the short run between meeting the volume targets and adaptability/accessibility standards given that much of the new housing stock being built today is not properly accessible.

Given the ageing of the population, people acquiring disabilities as they age and the social and economic benefits of people ageing in place, it is vital that the new housing stock that is built through NRAS is accessible.

DIG therefore recommends that NRAS should set clear adaptability/accessibility standards and only projects that meet these standards should receive a subsidy through NRAS, especially in the later years of the Scheme.

3. Income Threshold for Eligibility/Effective Tax Rates

DIG notes that the will be modelled on eligibility for Commonwealth Rent Assistance (CRA) or eligibility for the low income Health Care Card (HCC).

Currently, the Australian Government is considering a range of policy options to encourage greater workforce participation by people with disability and mental illness, because the participation rate for this group is much lower than the national average and the unemployment rate is much higher.

DIG has also been asked to consider barriers to the employment of people with disability as one of its Terms of Reference.

DIG would recommend some further consideration of the eligibility provisions for tenancy under the Scheme, with particular reference to people with disability and mental illness who have been successful in obtaining and retaining employment. Otherwise this group will face even higher effective marginal tax rates if they enter the workforce and so NRAS may unintentionally act as a further barrier to the employment of people with disabilities.

Summary of recommendations

DIG makes the following recommendations in response to the technical discussion paper:

1. DIG recommends that the Scheme should be amended by increasing the payment made in relation to housing for people with disabilities to recognise the higher costs of providing and servicing their housing.
2. In order to ascertain the required subsidy, DIG recommends that some detailed modelling be undertaken on both the level and structure of the subsidy and DIG would like to work closely with you on the development of further financial models, to ensure that housing for people with disabilities moves from the margin to the mainstream.
3. DIG recommends that NRAS should set clear adaptability/accessibility standards and only projects that meet these standards should receive a subsidy through NRAS, especially in the later years of the Scheme.
4. DIG recommends some further consideration of the eligibility provisions for tenancy under the Scheme, with particular reference to people with disability and mental illness who have been successful in obtaining and retaining employment. Otherwise this group will face even higher effective marginal tax rates if they enter the workforce and so NRAS may unintentionally act as a further barrier to the *employment of people with disabilities*.

Conclusion

DIG welcomes the opportunity to provide comments on the technical discussion paper on the National Rental Affordability Scheme and would welcome further engagement with FaHCSIA in the further development of the Scheme, as it applies to people with disabilities, including mental illness.

Yours sincerely,



Ian Silk
Chairman
Disability Investment Group

Appendix I

Summaries of Hope Villages Australia Urban Village Model and Foresters Community Finance (Foresters) and Parent to Parent Association QLD Key Housing Solutions Model

Urban Village Model

The summary contained herein is derived from information provided by Hope Villages Australia and has been verified by Mr Geoff McKeich of Hope Villages Australia. Claims about the proposed model and the legal implication of this model are those made by Hope Villages Australia not the Disability Investment Group (DIG) or the Department of Families, Housing, Community Services and Indigenous Affairs.

Background

1. Hope Villages Australia (Hope) made a submission to the DIG, detailing their Urban Village Model for supported accommodation for people with severe intellectual disability.

Hope Villages Australia

2. Hope is a not-for-profit organisation established to provide home ownership and supported life style options to people with severe intellectual disabilities currently living with ageing parents.

Housing Model

3. Under the Urban Village Model, Hope would establish a Unit Trust to enable a group of adults with intellectual disabilities to own property in a single name.
4. Present Hope modelling states that a unit in the Trust would cost \$170,000.00⁵ and would entitle each member of the trust to an equal share of the total property of the Trust and a Lifetime License to occupy a home in the village.
5. The model does not seek capital funding or additional benefits from the Government for the provision of accommodation.

⁵ The cost of a unit in a trust will vary across the States and Territories, \$170,000.00 is the initial cost of a unit in a trust for an Urban Village in designated regions in Queensland.

Accommodation

6. Under the Urban Village Model, accommodation infrastructure would be funded by the purchase of units in the Trust established and managed by Hope.
7. Hope would be the trustee of the Trust and would therefore be the legal owner of all assets held by the Trust. The Unit Holders would be beneficial owners, in that they have the right to the benefit of the assets held by the Trust.
8. Each Unit Holder is entitled to an equal share of the Trust's assets and the right to nominate a qualified person to reside in the Trusts Village for the whole of their lives, subject to the Unit Holders and Residents Agreement.⁶
9. Each Urban Village would be established under a separate Unit Trust.
10. Each Village would consist of normal residential dwellings specifically designed to meet the need of people with disability. One bedroom, two bedroom and four bedroom homes set in fully landscaped gardens will centre on a community centre, swimming pool and BBQ area.
11. Villages will be designed to accommodate around 100 residents. Four to eight residents in each village will have very high needs, with the remainder of the residents with care needs across the spectrum of need.
12. The demographics of the Village would be achieved via a thorough assessment process. Each Village would be made up of adult male and female residents of varying degrees of disability and age.
13. Right of transfer to any of the Hope developments, urban or rural, is automatically confirmed through the Unit Holders and Residents Agreements.
14. The value of the Trust Unit provides security for the Unit Holder against unexpected costs throughout their life, as provision is made within the Unit Holders and Residents Agreement for nominated expenses to be accrued against the Exit Entitlement of the Unit Holder.
15. The model has been designed to provide for the accommodation needs of the resident for the whole of their lives. As the residents age their compatibility with other residents may change, or through sickness they may need a different level of care. To accommodate these changes throughout the residents' lifetime Hope offers all residents the full range of accommodation options and the option to transfer without any additional capital cost to the Unit Holder.
16. When a resident no longer resides in the unit, the Trust will offer the unit at the current market value to a new resident. The 'outgoing' Unit Holder would receive an Exit Entitlement less deductions identified in the Unit Holders and Residents Agreement.

⁶ The Unit Holders and Residents Agreement (sometimes referred to as a Unit Holders and Licence Agreement) is the contractual arrangement between the person funding the purchase of the unit in the Trust, the resident and Hope. It sets out the resident's rights and entitlements pertaining to the Village within a life course framework.

Financing

17. Hope proposes that the parents of the adult with disability could finance the purchase of the unit in the Trust using a special mortgage secured over their own property. This would enable parents to secure funds to purchase the unit and obtain accommodation without having to make monthly repayments. The mortgage is only repayable subject to a defined event occurring including the parents selling the property.
18. On disposal of the parents' property, the mortgage debt is settled according to the current market value of the property and the equity percentage each party holds in the property created at the establishment of the mortgage.
19. The Unit Trust Holders (the parents) have the right to upgrade or downgrade their principal place of residence provided that the new property provides the mortgagee with the same or greater level of security.

Support Services

20. Whilst the management of the Village would be undertaken by Hope, an independent service provider would be contracted to provide the daily care requirements. Each resident would have an individual care management agreement setting out their care needs.
21. Under the model the Government would redirect the existing benefits currently received by the parent/carer, namely Carer Payment, Carer Allowance and associated respite program funding estimated at \$68,500 per annum.
22. Each resident will have an individual care management program including the specific requirements of the parents/carers across all areas of personal care and support. The Village carers will be required to maintain the standards set down as part of the service providers contractual obligations.
23. Modelling undertaken by Hope, in conjunction with House with No Steps, estimates that the average cost of support services would be \$50,000 per annum per person.
24. Residents, the cost of whose individual care management program exceeds the value of the redirected Government funding, would be required to make additional 'top-up contributions' to meet the cost of the care and support services.
25. Additional contributions and any other discretionary spending would most likely be funded by benefits, such as Disability Support Pension, Rent Assistance and Mobility Allowance, which would be payable to the resident.

Additional Information

26. As part of each Village's governance arrangements Hope will establish a Residents and Parents Council. This forum will be used to keep all concerned up to date and to plan forthcoming events and interaction between the Village and the community at large.

Key Housing Solutions Model

The summary contained herein is derived from information provided by Foresters Community Finance and Parent to Parent Association QLD. Claims about the proposed model and the legal implication of this model are those made by Foresters Community Finance and Parent to Parent Association QLD not the Disability Investment Group or the Department of Families, Housing, Community Services and Indigenous Affairs.

Background

1. Foresters Community Finance (Foresters) and Parent to Parent Association QLD (P2P), made a joint submission to the DIG, detailing a community economic development model, Key Housing Solutions, to mobilise social investment to provide secure housing for people with disability.
2. The submission also outlined impediments, on both the supply and demand side, to raising private investment in the community sector.
3. Foresters also provided additional information on relevant investment projects they are involved with.

Foresters Community Finance

4. Foresters is a community finance institution providing community finance, social investment and education for the third (charities, community groups) and fourth (social business and enterprise) sectors.

Parent to Parent Association Queensland

5. P2P is a network of parents and family members who have a child with disability. P2P facilitates families to assist each other by providing peer support, skill enhancement opportunities and networking, via local groups of parents in 12 locations across Queensland.

Key Housing Solutions

6. Key Housing Solutions is currently led by a working party comprising P2P, Foresters, the former Deputy Mayor of the Maroochy Shire and A Key for Me Ltd, a family driven accommodation support agency.

7. To implement the Key Housing Solutions model Foresters and P2P are arranging the formation of a Community Economic Development Company which will be supported by administration services provided by Foresters and governed by a board of up to seven directors.

Housing Model

8. Key Housing Solutions is a community economic development model, being used to mobilise social investment in a trust structure to secure long-term affordable housing and support for people with a disability.
9. The model utilises a holistic approach, focusing on individualised planning, community strengths and social investment, to produce social innovation. The three components of this holistic approach are:
 - Person Centred Planning (Futures Planning and Essential Lifestyle Planning): a process of focusing effort and attention around one person's individual needs to assist them to make plans for the future;
 - Asset Based Community Development (Community Facilitation and Community Development): a principle which advocates the use of skills and strengths of individuals within the community, rather than obtaining help from outside institutions; and
 - Community Economic Development: the practice of working with a community to develop and provide economic opportunities and improve social conditions in a sustainable manner.

Accommodation

10. In order to facilitate the provision of suitable affordable accommodation and other support for people with disability properties will be held by separate unit trusts.
11. The trustee of the unit trusts will be an associate company of Foresters.
12. In addition to being trustee of the unit trusts, the trustee will also provide services for Special Disability Trusts.
13. Properties will be rented to people with disability through formal rental agreements. The rental return will provide income to investors in the unit trust after the cost of rates, administration fees and maintenance has been deducted.
14. If the property meets the requirements of the National Rental Affordability Scheme it will be rented to an eligible person at a rate that is 20 per cent below market rate.

Financing

15. The model draws on integrated government funding, social investment and philanthropy:
 - government funding to provide support and to build community connectedness;
 - social investment to purchase accommodation; and
 - philanthropic funds to leverage the value of government funding and investment.

In the future, the application and value of earned income through social business activities will be explored.

16. It is expected that some capital will be invested in the Foresters Community Investment Fund and other capital will be invested directly in unit trusts.

Additional Information

17. Foresters and P2P initially intend to utilise the model to provide safe and secure accommodation to people with disability on the Sunshine Coast. Following this Foresters and P2P intend to duplicate the Key Housing Solutions structure for people with disability in Toowoomba and then in other areas.
18. A similar approach, to the Key Housing Solutions model, is also being developed by Foresters in conjunction with Wesley Mission and Mindcare Brisbane (an incorporated association that provides services to people with psychiatric illness).
19. The submission, made by Foresters and P2P, contends that the taxation and financial legislation and regulation of community economic development companies and community development finance institutions stunt the growth of such entities and consequently inhibit private investment in the community sector.
20. The submission also provided comment on impediments on both the supply and demand side to raising private investment in the community sector.
21. The submission identified 8 supply impediments to investment in the community sector. These are impediments internal to the community sector including structural considerations, low rates of return on investment and under funding.
22. The submission also identifies 18 demand impediments. Demand impediments are those external to the community sector, including the lack of metrics for social return on investment, regulation and compliance costs and limited government support.

Appendix J

National Disability Research Institute – Draft Charter

The Australian National Disability Research Institute (ANDRI) will provide leadership and support for strategically directed research into disability related issues. It will help to convert evidence into appropriate policy and practical assistance for Australians who have disability, their families and carers. The Institute will work to promote partnership and collaboration to foster research with practical outcomes and prospects for commercial application.

The role of the Institute will be to operate as a point of coordination and facilitation of:

- parties involved in or interested in undertaking research on disability related issues;
- best practice and identification of leading practitioners;
- the development and propagation of information on the commercial application of disability-related proposals; and
- dissemination of data and research findings.

The Institute will be at the pinnacle of disability research in Australia, combining international best practice with current thinking and research in Australia. It will operate across a variety of institutions, and will be open to all interested participants and investors, as a means of promoting collaboration and growth in the area.

Objectives

The objectives of the Institute are to:

1. develop the capacity of the disability research sector;
2. foster best practice and excellence in research on disability-related issues;
3. encourage and facilitate increased private investment into disability research;
4. establish and articulate national priorities in the field of disability research;
5. consolidate and harness existing research efforts on disability-related issues;
6. identify and work to address gaps in current disability-related research;
7. promote collaboration, both nationally and internationally, between and within academia, government, industry and disability-oriented professionals and service providers;
8. encourage and facilitate disability-related research with practical outcomes and applications;

9. provide a means of linking opportunities, commercialisation, industry, engineering and medical research with government policy;
10. facilitate translation of research effort and outcomes into practice and policy;
11. work with national and international partners to identify and develop sources of accurate information;
12. provide advice on opportunities relevant to and issues affecting the disability sector to build a policy, regulatory and industry environment conducive to research; and
13. collect and efficiently disseminate information on the strength and value of disability research; current and potential research activity; and data and research findings.

Priorities

ANDRI should give priority to research which:

- is directly relevant to the lives of people with disability;
- is translatable into evidence based policy and practice;
- has practical outcomes and applications;
- engenders commercial application or partnership with industry;
- covers a range of research across national interest projects, commercially viable projects and data collection; and
- encompasses the broadest range of policy relevant social research, practice research, engineering and technology and medical research.

Funding Arrangements

The Institute will have core funding from government but will be expected to find additional philanthropic and commercial funding as well as funding through other competitive government grants, such as through National Health and Medical Research Council and Australian Research Council grants. It would also harvest the relevant research from other disciplines. Initial funding will be \$10 million per annum within the National Disability Agreement. Future funding should also be sourced through the proposed National Disability Insurance Scheme.

The Institute will also provide funding to individuals, organisations and research bodies undertaking or proposing to undertake specific research within the priority areas.

The Institute will be expected to cover the following broad types of research and likely funding sources:

- national interest activities, such as policy, advocacy, research and data collections, where there was no prospect of a commercial return and the most appropriate funding source is government funding;
- projects capable of earning a commercial rate of return, where funding could be sourced by companies prepared to invest with the expectation of market rates of return; and
- projects which were not national interest and not capable of earning commercial rates of return but which are important to quality of life, which would most likely be funded by government funding, philanthropic organisations or a combination of these.

Governance Arrangements

The Institute will receive high level scientific, strategic and business direction and support through strategically focussed governance arrangements. The Institute's governing body should include persons with broad engagement with industry and philanthropy, including people with commercial experience and skills and more traditional academic research experts, as well as people with disability, their families and carers.

In considering the commercial application of research, there will be a need to forge relationships with industry to provoke more thinking about how to translate research into what is needed and to be results oriented. This will need strong early engagement with the commercial sector as potential customers for research work.

Future governance arrangements should secure collaboration between the Institute and the proposed National Disability Insurance Scheme. The scheme could also provide future funding for the Institute. The Institute should be able to utilise de-identified data collected through a future scheme which would generate a comprehensive Australian longitudinal data set for people with severe and profound disability.

