

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.

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,

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

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.

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 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).
- 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

| Year | Current programs (\$b) | | NDIS | | | NDIS Net cost components (e) | | Growth funding needed (\$b) | | |
|------|------------------------|--------------|------------------|---------------------|---------------------|------------------------------|---------------------------|-----------------------------|----------|------------------|
| | 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.

Error! Reference source not found. 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

Governance Structure & Prudential Management

Governance options (consider a range of options and their advantages, including international and Australian examples)

Cost modelling (develop a detailed demand and utilisation model, extending the work of DIG and conducting a need/gap analysis)

Revenue modelling (consider a range of options for revenue, including projections linked to economic/demographic forecasts)

Data requirements (develop data requirements across the spectrum of streams and feeding back to utilisation, outcomes and governance)

Investment management (investigate investment management options, including links to the Future Fund/Superannuation models)

Insurance concepts (explore advantages of the insurance model of risk sharing, liability management & prudential oversight/feedback)

Stakeholder Engagement & Consultation

Develop a strategy for stakeholder engagement (aimed at concept explanation, pros & cons, engagement and participation)

Commonwealth (Central agencies [PM&C, Treasury], Human Service agencies [FaHCSIA, Health, DEEWR], and other related agencies)

States and Territories (equivalent agencies to the Commonwealth, plus accident compensation, civil liability and health care liability bodies)

Service providers (peak bodies and agencies engaged in service delivery of all types, including academic partners and researchers)

Carers (peak bodies and carers representing the needs and interests of providers of unpaid care to people with a disability)

People with a disability (peak advocacy bodies and individuals, whose needs and potential are at the centre of the support framework)

Assessment & Review Requirements

Need type definitions (establish the types and quantum of care and/or support requiring coverage and support by the scheme)

Expert panel engagement (assemble the recognised experts on linking need and demand to measurable constructs and instruments)

Functional assessment (explore suitable classifications and instruments for establishing (a) eligibility and (b) level of need for care and support)

Need and assessment management (explore operational issues related to assessment timing and frequency and utilisation monitoring/feedback)

Appeals and review mechanisms (explore issues around the nature of review and appeals, including the structures in similar schemes)

Sensitivity testing (link different eligibility and entitlement options, with service caps and options, to cost and liability modelling)

Care and Support Management

Network development options (consider the required service provision network and infrastructure vs existing State structure)

Care & support requirements (consider the types and range of services required, considering the need and demand expectations)

Service provider engagement (consider how service providers can be engaged and/or developed, and requirements of them)

Individual planning & monitoring (consider how individual client potential might be realised through personal planning, application and outcome monitoring)

Case management (investigate insurance-type models of case management, care coordination and individual plan monitoring)

Workforce development (determine workforce needs to deliver expected demand, and investigate options to generate this workforce)

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.

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.

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 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.

- 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

- The need for the Commonwealth Government to endorse and take action on the Senate Committee's Report and recommendations on Special Disability Trusts (SDT).
- The lack of endorsement of SDTs by professional bodies/organisations such as public trustees and lawyers.
- 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

- 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.
- 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.
- The importance of developing leadership capacities of people with disability to enhance employment opportunities.
- 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 principle 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.

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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 | X | ✓ | X | ✓ | ✓ | ✓ | X |
| National Joint Replacement Registry | ✓ | ✓ | X | ✓ | ✓ | ✓ | ✓ |
| IDEAS Disability Info Line Service User Records | X | ✓ | X | ✓ | ✓ | ✓ | X |
| Intellectual Disability Exploring Answers (IDEA) Database—WA | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |
| Australian Cerebral Palsy Register | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| The Spastic Centre Client Database | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |
| WA Register for Autism Spectrum Disorders | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |
| Motor Neurone Disease Database | X | ✓ | X | ✓ | ✓ | ✓ | X |
| Australian Motor Neurone Disease Registry | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Australian Twin Registry | X | ✓ | X | X | ✓ | ✓ | ✓ |
| National Trauma Registry Consortium (Australia & New Zealand) | X | ✓ | X | ✓ | ✓ | ✓ | ✓ |
| Australian Cystic Fibrosis Data Registry | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Australian Longitudinal Study on Women's Health: Older Cohort, Wave 4, 2005 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Patients of NSW Developmental Disability Health Unit | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |
| I-CAN Instrument for the Assessment and Classification of Support Needs | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |
| Epilepsy Action, Australia | X | ✓ | X | ✓ | ✓ | ✓ | ✓ |
| Tasmania Epilepsy Register | X | ✓ | ✓ | ✓ | ✓ | | X |
| Australian Rheumatology Association Database | X | ✓ | X | X | ✓ | ✓ | ✓ |
| Australian Rehabilitation Outcomes Registry | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| National Genetic Heart Disease Registry | X | ✓ | X | ✓ | ✓ | ✓ | X |
| Australian Spinal Cord Injury Register | ✓ | ✓ | X | ✓ | ✓ | ✓ | X |
| Victorian State Trauma Registry | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |
| Victorian Orthopaedic Trauma Outcomes Registry | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |

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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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,

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

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.