Submission to Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme

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Priorities for action

Taking up options canvassed in the Discussion Paper, the starting point for this submission is the expectation that additional funding will become available for disability services, possibly through a social insurance scheme. The Disability Investment Group has established the need additional funding and means of generate these resources. This submission focus on priorities for using these new resources to maximise benefits for people with disability not simply by providing more of the same services as the present system offers, but by driving change and restructuring across the disability services system. Decisions on how additional funding is to be spent are of course not unrelated to decisions as to the sources and levels of new funding, and setting some priorities is seen to be essential when the disability system as a whole is under-resourced.

The first priority identified in this submission is for a new **Catastrophic Disability Insurance Scheme** (CDIS) as a spearhead for wider change. CDIS is used here as a label for what has elswhere been called a National Disability Insurance Scheme, to indicate coverage is limited to those with disability that is catastrophic in its causes and effects. This new component would inject additional funding for the support a small group of highly dependent individuals whose complex support needs lead to very high costs. This group are referred to as “exceptional” clients in this submission.

Establishing a CDIS would generate change in other components of the disability system that are each focused on somewhat different client groups who need different sets of services. These components and priorities for change are:

- **A National Injury Compensation Scheme:** As well as harmonising existing transport, workplace injury and medical negligence schemes, and providing national cover with funding through risk based premiums, a further priority for change in this component is a move to provision of long term support, including slow stream rehabilitation, through structured settlements and away from lump sum payouts.

- **A Disability Services Program:** The priority for change in this component is to bring together CSTDA services and funding with services and funding for younger people delivered through HACC, with development to proceed through a new CSTDA. Relieving this program of the exceptional client group could be expected to free some 20% of current to serve a broad and diverse target population.

- **An Assistive Technology Benefits Scheme:** This scheme addresses the priority need to replace the fragmented provision of aids and equipment through existing State and Commonwealth programs.

- **A Community Disability Living Allowance (CDLA):** This Allowance addresses the priority of promoting client choice by paying a cash benefit directly to all individuals with a defined level of disability. A CDLA is seen as a better option for promoting consumer choice than cashing out funding for services and would be phased in to replace the Carer Allowance (but not the Carer Payment).

The rationales for this multi-component approach include:

1. The **exceptional client group** has been widely identified but remains poorly served by current arrangements. Addressing this problem is identified as the highest priority, not only for the individuals concerned but to drive change in the wider disability system. The experience of the High Care Pool established by the NSW Home Care Service, outlines below, demonstrates that action focused on this group can achieve positive outcomes at both individual and system levels.

2. **Injection of new funding** for the CDIS through a social insurance levy is considered most appropriate as disability among these clients is often catastrophic in cause and can be linked to an insurable event and risk. The CDIS would include all causes of catastrophic disability, including congenital and acquired disability, that are not covered by existing compensation schemes.

3. **Concentrating additional funding** on a CDIS would provide a much stronger focus and impetus for restructuring than a thin spread of funding across the whole of the disability services system. High visibility of a CDIS, including the establishment of an independent body to administer it, possibly as an adjunct to the Health Insurance Commission, would make it an effective driver of wider change. This body could also assume some of the responsibilities for a reformed national compensation scheme in conjunction with state agencies.

4. Additional funding directed to this exceptional group would **relieve pressure on the rest of the disability services system** and open the way for reforms to enhance equity of access and consistency of support to clients receiving services through other components of the overall Long Term Disability Care and Support Scheme.

5. Implementation of a coherent multi-part scheme is seen to be **less disruptive and to stand more chances of success** than moving to new way of funding for all clients currently receiving disability services and for all the agencies delivering these services; harmonising compensation schemes is also a preliminary to any further development.

6. **Review** of the CDIS three to five years after implementation would allow for revision of its' scope in the light of funding experience and outcomes not only for CDIS clients but for clients and providers in other parts of the overall Long Term Disability Care and Support Scheme, and identify opportunities for advancing other options such as integration with the injury compensation insurance based component of the overal Scheme.

Background

This submission draws on ideas developed from consideration of many aspects of disability services over some years, including targeting of community care services in relation to dependency, consumer directed care and direct payments, and social insurance for long term care.

As most of my work has been in aged care rather than disability, particular attention is given to areas of similarity and difference between the two fields, and to the interfaces between the two systems.

PART 1: Issues in development of a Catastrophic Disability Insurance Scheme in a Long Term Disability Care and Support Scheme

1. Clarification of target populations, eligibility and entitlement

1.1 Conceptual and practical clarity

Some further discussion is required to differentiate the concepts and practicalities of defining

(a) the target population for any program,
(b) eligibility for the services provided under the program, and
(c) entitlement to particular kinds and levels of services.

The view that eligibility confers entitlement is not only misleading for members of the community but can distort the picture of the potential need, and hence cost, that could arise under different elements of a new approach to disability services, especially a CDIS.

The difference between these concepts can be illustrated by reference to Medicare. The *target population* for Medicare can be taken as the whole Australian population as it provides universal coverage. However, individuals only become *eligible* for services provided through Medicare in the event of illness. Access is then based on need for health care, as assessed by a health care professional who has a Medicare Provider Number. It is only after this assessment that the individual is *entitled* to receive funding for a particular service, and in most cases, for a limited time.

Access under Medicare is also controlled by a number of supply side and demand side measures. On the supply side, Medicare covers a wide range of, but not all, health care services and the items on the benefits schedule change from time to time. Other supply controls are the range and number of health care providers in any locality who are approved Medicare providers. Demand side measures include not only co-payments and waiting times to see a GP or for elective care in a public hospital, but a number of other health promotion programs and primary care services that complement Medicare.

Like Medicare, a CDIS could provide universal cover for all Australians, who would become eligible in the event of catastrophic disability, and entitled to services determined on the basis of extensive and expert assessment. Access, and hence cost, would also be controlled through a number of supply and demand side measures.

1.2 Comparison of SDAC and Census data

The Discussion Paper notes the difference in the number of younger people with severe and profound disability identified in the ABS Survey of Disability, Ageing and Carers (SDAC) compared to the Census. The Discussion Paper goes on to state that the SDAC figure is generally regarded as more reliable. The difference is not however one of statistical *reliability:* the Census would have to be more reliable as a complete count compared to the SDAC estimates based on a sample survey.

The difference is one of *comprehensiveness* with regard to the scope of disability covered. The ABS Census Dictionary emphasizes that the method of collection in the Census and the reduced question format mean that the data should be taken as an indication of characteristics of people who report a need for assistance, but is not the same as the total prevalence of profound or severe limitation reported in the SDAC.

- The 2006 Census form required an answer to a single question to establish whether the person had a need for assistance, from either an informal carer or a formal service, in carrying out core activities but did not differentiate profound and severe limitations, or distinguish between need for assistance in self care or mobility vis-a-vis communication difficulties.
- The SDAC covered a wider scope of disability as it asked a series of questions to determine the level and nature of disability for the total population living in the community and included questions on disability affecting education and employment among the population aged under 65.

1.3 Defining Target Populations

The methods used in both the SDAC and Census are designed for collecting data on the prevalence of varying levels of activity limitation across the population and the definitions used accord with WHO classifications designed for this purpose. These data are highly appropriate for defining broad target populations for different programs and SDAC data have been used for this purpose for many years.

Most notably, the target population for the HACC program is defined as those with moderate, severe or profound limitations. A comparison of the target population defined using SDAC and Census data, for the population aged 65 and over, found that the difference in the size of the target populations and numbers of carers could be readily reconciled when methodological differences were taken into account, confirming the reliability of both data sets (Howe, 2008). That analysis concluded that a broader rather than narrower definition of the target population was appropriate given the aims of the HACC program and a range of evidence as to the effectiveness of the kinds of support services provided through HACC for those with moderate limitations as well as for those with higher levels of disability. That analysis could usefully be replicated for the younger age groups.

The effect of redefinition of the target population in term of level of activity restriction is substantial. SDAC data indicate that a target population of 3.9m defined as all those with disability reduces progressively to 1.9m when restricted to moderate, severe and profound limitation, and to some 600,000 if limited to profound limitation only. These differences represent reductions of 53% and 85% respectively compared to the first definition. The group of exceptional clients would be much smaller again.

Even though the SDAC identified target population is more inclusive than that identified using Census data, it does not follow that *either* is the right or a better definition for the purposes of an CDIS. Rather, as with the HACC program, the target population must be defined in relation to the aims and objectives of the scheme itself.

Detailed analysis of the 2009 DACS and 2010 Census data will provide a set of best estimates of target populations based on different levels of disability. Analysis aimed at identifying those with profound limitations in multiple activities would provide a view of the possible number of 'exceptional' clients. In the first instance, it can be assumed that the exceptional client group would include the 16,500 younger people with disability living in institutions and residential care settings, including group homes, and some 6,500 people under 65 living in residential aged care homes. Allowing for half as many again, 11,500 living in the community, most with substantial levels of family care, the total group might be in the order of 35,000. This estimate approximates 5% of those with profound limitations.

1.4 Sensitivity and specificity

The criteria of sensitivity and specificity that are commonly applied in assessing the validity of diagnostic testing in health research can be applied to definitions of target populations:

- to meet the test of sensitivity, a target population definition should include those the program is intended to serve, and
- to meet the test of specificity, it should exclude those who are not potential beneficiaries.

A poorly defined target population that either includes many who should not be included (false positives) and/or excludes many who should be included (false negatives) distorts the view of need for the services being provided. The target population thus has to be defined in accord with the aims of the program, the scope of services it is to provide and who is expected to benefit from those services.

In the case of a CDIS focused on those with exceptionally high levels of complex disability, a narrower definition would be appropriate, with both need and support responses based on in-depth assessment. This target population would be smaller than the number identified in the SDAC as having a profound limitation as not all of the latter group need very high levels of support from multiple services. While a much smaller number would be assessed as entitled to support, all would be expected to receive a high level of support through individually tailored packages with different mixes of services.

An example of a narrow target group is that defined for the High Need Pool established by the Home Care Service of NSW as a pilot program in 1998. The Guidelines state that "to be eligible for the High Need Pool, there must be a minimum need of 15 hours per week (60 hours per 4 week period) and a maximum need of 35 hours per week (140 hours per 4 week period). The amount of approved hours will be determined by a number of factors including assessed need, available resources at the time of approval, levels of informal and formal support available at the time and current Departmental policies on targeting". In 2008-09, the High Need Pool served 520 clients, most under age 65, with funding within the HACC budget of HCS. It runs alongside the Attendant Care Program which serves 740 clients, all aged under 65, operated as part of HCS disability services Clients of both these services are characterised by very high users of personal care. Figures in the 2008-09 Annual Report of the NSW Department of Ageing, Disability and Home Care show that 500 clients in the two services accounted for only 3% of all HACC clients using personal care, but they accounted for 25% of all personal care hours. The High Need Pool has proved to be an effective means of providing intensive support packaged to meet needs of high needs client across the state at the same time as using centralised management and service caps to protect the budgets of individual HCS Branches to provide services to the much larger number of clients with lower service needs. The number of places in the High Need Pool is however inadequate and waiting lists exist.

A wide definition would be appropriate for the parts the disability scheme that continued to cover a wide range of services, akin to those currently provided under the CSTDA and through HACC to younger people with disability.   Clients would receive widely differing levels and types of services.   For consistency with the HACC program that provides services to substantial numbers of younger people with disability, the target population for this component of the overall disability scheme should include those with moderate as well as severe and profound limitations, aged under 70 years.   (It is emphasised that this age definition is for planning purposes only; see Part 2 for further comment). While increasing the size of the target population, the impact on service use is far less as many will make only occasional use of small amounts of service, but doing so will be of considerable benefit to them and their carers. Conversely, actual or perceived exclusion from the target population and from eligibility to seek services can create undue anxiety and possibly perverse behaviour in order to qualify for services.

1.5 Defining eligibility compared to assessment of need

While coming within a target population defined on the basis of the ABS data can be taken as defining eligibility for services, neither the SDAC nor the Census methodology are designed to be an assessment of need for particular types of services, and should not be used as an indicator of the numbers who might receive one or other service following the assessment of need.

Further, the difference between the target population and the number of recipients of services under any program provides only a very basic guide to unmet need. Unmet need instead has to be assessed with reference to particular kinds of support provided under any program, and where relevant, taking account of informal care.

A case in point is the comparison made in a recent paper by The Australia Institute (Baker, 2010) between the 416,900 recipients of Carer Allowance (CA) and the 532,532 carers identified on the basis of the SDAC (adjusted to the 2008 population).   The conclusion reached was that some 20% of carers were missing out on CA. However, this conclusion fails to take account of the more stringent criteria applied in assessing eligibility for CA which mean that not all carers in the target population (as defined by the SDAC) qualify.   Once a carer meets the eligibility criteria, they are entitled to receive the CA.   An alternative interpretation of these figures is that coverage of CA is high, at around 80% of the potential target population.   This example demonstrates the mediating effect of eligibility criteria on filtering recipients from among all those in a target population who may be potentially eligible.

1.6 Assessment of need and entitlement to needed services

The Discussion Paper refers to a number of tools used for assessing need for particular kinds of support and care services, and the level of care needed.   It is very clear that these tools, whether involving self-assessment or administered by a professional practitioner, are very different to the ABS methods, and that an array of valid and reliable clinical tools are needed for assessment of different kinds of disability and care needs.

A further distinction needs to be made between tools designed to assess level of disability and decision making tools that guide service responses.   This distinction is especially pertinent to assessment for eligibility for services provided under the HACC program and the CSTDA as the relationship between level of dependency and service is far from direct. Extensive research into targeting in the HACC program has found that:

- very few people with low dependency made use of any services;
- while high levels of service use were related to high levels of dependency, many highly dependent clients made only very limited use of services;
- use of any service compared to none was found to reduce the likelihood of a recommendation for admission to high level residential care (nursing home care); and
- there were diminishing returns to continuing increases in service provision at high levels of dependency.

The main conclusions of this research were that:

- provision of initial service achieved the greatest reduction in risk of admission;
- low levels of service use indicated a high need for that support rather than being equated with low dependency or low need;
- thresholds for access to support should be set lower rather than higher; and
- provision of additional support should be judiciously managed.

Relationships between level of dependency and support needs are likely to be even more complicated among younger people, given the diversity of disability and needs for educational and employment support as well as personal care, home care and social support. So while all those in the target population may be eligible to seek services, entitlement is not automatic but depends on assessment of need for particular kinds of services and level of support required. There is a recognised need for more consistent and system-wide approaches to assessment for disability services, using tools that are widely accepted in the field. Determination of the level of service or funding that should follow on from assessment is a complex task, but it is a task that must be undertaken.

The extent to which entitlement to particular kinds and levels of assistance follows on from assessment of need also depends on a number of supply side factors. Apart from income support programs, few programs are truly open-ended in that meeting the eligibility criteria automatically confers uncapped entitlement to services. The use of service caps in the HCS High Care Pool is a case in point. In general, access to services is usually subject to a number of demand and supply side constraints. By way of example, having a prescription issued by a GP entitles the recipient to subsidised medicines under the PBS which is seen as a universal and fairly open ended program. However, demand side controls are imposed by way of co-payments and limits on repeat prescriptions, and supply side controls limit the range of pharmaceutics supplied, prices paid to manufacturers are set, and outlets are restricted to registered pharmacists.

1.7 Beginning a CDIS with a narrow target population

There are several grounds for beginning a CDIS with coverage of the much smaller population of exceptional clients who experience very high levels of disability, and who need high levels and multiple kinds of support, for very extended periods, and at very high cost.

The primary reason is that these individuals are least well catered for at present. Notwithstanding high levels of service use in some cases, access for individuals is inequitable and the uneven spread of burdens across the service system affects access for others.

Second, addressing the needs of this small group would have wider benefits as a CDIS would relieve pressure on CSTDA programs and HACC as the small percentage of most dependent clients use a much greater share of services and resources. Relieved of these exceptional clients (or reimbursed for delivering services to them), service providers would then have the resources to provide more support their wider target populations. The impact of the CDIS in the community, and the scale of funding required, would depend on the pace at which the CDIS would take over responsibility for funding care of existing exceptional clients vis-a-vis newly catastrophically disabled clients. Transition arrangements might see coverage first for those living in the community with disability and service support equivalent to clients in the NSW HCS High Care Pool, and later extending to those in disability supported accommodation by negotiation under a revised CSTDA, with a key condition being the transfer of all existing State and Territory funding to community based disability services. It is recognised that neither the number of places equivalent to the NSW HCS High Care Pool or in existing disability supported accommodation are adequate even at present and futher community and accommodation places are required.

Third, it is likely to be more practical to begin with a narrow target population, clear eligibility criteria and comprehensive assessment, and allow for later expansion, than to begin with a wider target population and run the risk of having to contract coverage at a later date. This approach would be less disruptive for many clients and carers than a whole scale change across the disability sector. Rather than subsuming the totality of disability services, the CDIS would run alongside other on-going programs which would undergo reform generated by introduction of the CDIS.

Fourth, the extent to which a CDIS would affect providers of disability services will be shaped by the proportion of any agency’s clients who would transfer to the CDIS. The likelihood of agencies having to deal with the CDIS alongside other programs, will be affected by the size and nature of the client group coming under the CDIS and the range of services covered. A smaller group of clients, at least initially, will limit the number of agencies affected as not all disability and community care agencies are serving clients who would qualify for CDIS support.

Agencies supporting CDIS clients could be designated as CDIS agencies. Designated agencies are likely to be larger providers delivering a range of services, or more specialised agencies serving particular client groups, but the designated agency would be expected to provide the major part of care services used by its CDIS clients and contract only for a small part of services. Models for this mixed approach are already in place in community care agencies that deliver packaged care to younger clients with disabilities and frail older clients by combining direct delivery of some services with brokerage of other services.

Experience with Community Aged Care Packages suggests that models of ‘internal’ brokerage have been more sustainable, more easily administered and more cost effective than full budget holder approaches or ‘external’ brokerage models that rely on extensive contracting. Under ‘internal’ brokerage, a case manager employed by the provider agency develops a care plan with the client and services are then ‘contracted’ from the same provider, except for specialist services that may need to be contracted from other agencies. Agencies that were initially set up purely as brokerage agencies have tended to hire their own care staff and reduced the number of external providers with whom they have to contract. As well as driving a move to internal brokerage, the complexities of dealing with multiple brokerage contracts has lead other community care agencies to seek package places that they can deliver to their own clients instead of having to respond to multiple contracts of other provider.

2. Balance of services and cash benefits

2.1 Australia in international context

Given that there is limited experience with consumer directed care or direct payments in Australia, discussion of options for funding for services to be 'cashed out' has been informed by international experience. A Discussion Paper prepared for Alzheimer's Australia (Howe, 2003) identified a number of elements of cash benefits already existing in the Australian system and concluded that consumer direction should be an option in Australia's community care system, with models developed to suit the local context. Since then, interest in consumer directed options has increased and while stronger among younger people with disability, it appears that demand is tempered by a number of factors affecting the service system and related cash payments.

Local Authorities in the UK have had to offer Personal Budgets, now known as Direct Payment, for more than a decade. Figures reported in the *Community Care Statistics 2008-09: Social Services Activity Report, England*, published by the NHS Information Centre for Health and Social Care (www.ic.nhs.uk), show that Direct Payments were more popular with younger than older clients receiving community based social care:

- Of the 86,000 clients receiving Direct Payments in 2008-09, 57% were aged 18-64 and 43% were aged 65 and over.
- The 49,000 younger recipients of personal budgets accounted for 9.4% of all younger community care clients, while the 37,000 older recipients accounted for only 3.6% of all older clients.
- By comparison, 124,000 younger clients (24%) used aids and equipment, the most commonly used service, and 110,000 used home care (21%).

The UK experience points to a number of factors that appear to affect the choice of Direct Payments rather than services, and which are likely to have a bearing on take up in Australia. These include the availability of other cash benefits for people with disability and the availability of care workers, including low paid, casual workers in the 'grey' economy.

2.2 Availability of other cash benefits

Disability Living Allowances are paid in the UK in addition to income support. In 2008-09, 2.9 million people aged 18-64 received DLA, ranging from a minimum of just under £20 to a maximum of just over £120.00 per week. Another 1.5 million people aged 65 and over received the equivalent Attendance Allowance.

In Australia, the Carer Allowance represents a significant element of cash payments in the care system. While the level of CA paid to individuals is low, total outlays are substantial. In 2005-06, total expenditure on CA (Child and Adult) was $1.258 million, close to 90% of the $1.4m spent on the HACC Program.

There are no restrictions on the way CA can be spent and it appears that some recipient use it to 'top up' subsidised services by paying for additional hours of service delivered by the same agency where this is possible. It appears that many clients and carers are satisfied with a mix of services and cash benefits rather than expressing a strong preference for cash benefits alone.

The ease with which cash benefits can be used to purchase care services depends on the availability of workers willing to take on such work, generally at low rates of pay and under irregular working conditions. Aspects of the Australian labour market and working conditions mean that such workers are much less likely to be available than in many other countries. The difficulties that community care providers report in recruiting and retaining staff suggest that individuals may face considerable barriers in engaging home care workers, and further barriers arise in the preferences of workers themselves for standardised work conditions and rates of pay. These workforce factors also appear to have limited the growth of a care market of commercial providers developing on any scale in Australia .

2.3 Scope of care services under consumer directed care

The scope of support that the ‘care’ in Consumer Directed Care refers to warrants discussion. Is it only a set of specified care services, or “whatever it takes” to keep on caring for the client in the community, including a wide range of lifestyle choices that would normally be seen as discretionary spending on the part of the client and/or the carer?

To the extent that the main restriction on choice in delivery of care services is limited supply, the solution is to increase supply. Simply redirecting existing levels of funding through consumer directed care could lead to payment of a premium for a selective set of services rather than increasing overall supply, and indeed could prompt a rise in price for a constant supply of services. There is little evidence to suggest substantial prospects for a market response by way of increased commercial provision of care services, notably personal care and attendant services, as distinct from currently available domestic cleaning, home maintenance services, personal alarms and monitoring services.

The main restriction on the lifestyle choices for many people with disability is low income, and the solution here is an increase in pensions and allowances such as the Carer Allowance and Carer Bonus which would allow more choice in discretionary spending.

2.4 Alternative approaches to cash benefits

a) A Community Disability Living Allowance

Notwithstanding the value of the Carer Allowance as recognition of the role of carers, it is subject to two major criticisms:

1. There is a strong view that allowances for the additional costs of disability should be paid to the person concerned and not the carer. In accord with promoting consumer choice, the individual would then have full control over how the funds were spent. Payment to the carer may instead limit the choices of the individual. While there is no longer a requirement for co-residence for receipt of CA, payment to the carer may limit the choices of young adults who wish to live more independently of their family carer.
2. Those who do not have a carer but who experience the same additional costs are disadvantaged.

These criticisms could be addressed by replacing the CA with a Community Disability Living Allowance, paid directly to the person with disability regardless of whether or not they had a carer. The UK Disability Living Allowance noted above provides an example.

b) Compensation payments through structured settlements

There are strong grounds for replacing lump sum payments for accident and injury compensation with structured settlements that cover care services as well as loss of income.

A move to structured settlements should be part of the harmonisation of compensation schemes to ensure that compensation payments are applied to their intended purpose over the long term. Together with payment for slow stream rehabilitation, this alternative approach would ease some of the pressure that otherwise falls on CSTDA and HACC services when lump sum payments are exhausted.

A barrier to structured settlements to date has been insurers' reluctance to maintain long term contact with clients. This barrier could be overcome by having structured settlements managed by the same independent agency that administers the CDIS.

3. Provision of aids and equipment

Aids and equipment are highly valued by people with disabilities as a means of enabling them to be independent of support from other people. Assistive technologies (AT) are also valued by carers as they free time for other activities and can reduce the risk of injury to the carer and the person they care for.

While use of aids and equipment is reported to be high (AHIW), there are inequities, inconsistencies and inefficiences in access to different types of AT under different programs and between jurisdictions. Major inequities have developed between the States and Territories in the wake of the phasing out of the former national Program for Aids for People with Disabilities (PADP), with some states maintaining much greater commitments than others. There are also differences between states and even between areas within states in access to aids and equipment through public hospitals, through the Home and Community Care Program and other State programs, including disability packages. Over-the-counter access to aids and equipment through pharmacies and specialist retail outlets has expanded in recent years, but many potential purchasers face cost barriers. There is little if any quality assurance to promote the use of the most effective aids or value for money.

These problems could best be addresses and equity and efficiency goals pursued through establishing a National Assistive Technology Benefits Scheme (NATBS) which focused on providing aids and equipment for daily living rather than for rehabilitation. Along the lines of the PBS, features of a NATBS would include:

- Coverage of a specified list of AT items, ranging from low tech to high tech, with low tech low cost items limited to therapeutic items and excluding items regarded as everyday convenience tools.
- At prices agreed with AT suppliers;
- A range of participating outlets, including outlets providing rented equipment and providing repair and maintenance services;

- ‘Prescriptions’ written by approved assessment agencies, including but not limited to Aged Care Assessment Teams. Assessment agencies would be assigned a notional annual budget and be required to keep the cost of prescribed AT within that budget.
- Coverage of a target population aligned to the HACC program, recognising that use of AT by many of those with moderate limitations can reduce progression to higher levels of disability.
- As with the PBS, an NATBS would cover all age groups and could include specific provisions to improve effective and efficient provision of aids and equipment in conjunction with funding of residential aged care and other residential care for people with disabilities.
- Special provision for approval of extremely high cost items that would require assessment by a panel rather than individual assessment agencies.
- The cost of aids and equipment for CDIS clients could be provided through the NATBS on a cost recovery basis.

The national network of Independent Living Centres have been working on the development of nationally consistent arrangements for access to AT and these centres are a key source of advice on the development of a NATBS. The Australian Institute of Health and Welfare has also prepared a number of reports on use of AT. Internationally, the experience of Norway provides an example of best practice that shows how a cost effective and equitable scheme could operate.

A NATBS would bring other benefits such as advancing Australia’s contribution to R&D in the field of assistive technology to complement R&D in other fields of health care and medicine, especially rehabilitation medicine.

4. Strengthening prevention in conjunction with a CDIS

It is surprising, and indeed disappointing, that the need for increased measures to reduce the incidence and prevalence of disability is not raised until near the end of the Discussion Paper (p. 44). The capacity for a range of measures to be taken to prevent and reduce the impact of disability in conjunction with a CDIS should be given far more attention.

This potential is well demonstrated in the success of traffic accident schemes and work safety schemes in reducing injury and rehabilitating injured people, and as a result, containing the cost of those schemes in terms of premium levels and in reducing the burden of disability for individuals and the community as a whole.

Important adjuncts to an CDIS should be monitoring and research in a number of areas. Better understanding of the causes of the classes of disability covered by an CDIS could identify the scope for primary prevention, including congenital disability and the relatively rare but severely disabling illnesses with mid-life onset, such as MND and MS.

Research could also point to areas in which premiums might be scaled in order to drive down disabling injury. Motor accident and workplace injury schemes place penalties on what are regarded as injurious goods and practices, and if monitoring of the causes of catastrophic disability identified similar risks, at least part of the cost could be carried accordingly. Alcohol stands out as the most likely candidate, but high risk recreation activities could also come under scrutiny. Thus, just as premiums for workplace injury and motor accident premiums take account of safety records, CDIS premiums paid by licensed venues and other high risk businesses could be scaled in accord with their safety record.

Research into rehabilitation following injury and educational approaches for intellectual disability are also areas requiring much greater research effort.

PART 2. Interfaces between disability and aged care

1. Introduction

The proposal that a new disability scheme should provide care for the life of an individual who experiences severe disability before age 65 (or any other specific age) raises a number of questions about arrangements for care for individuals covered by the CDIS whose care needs come to be dominated by limitations stemming from ageing related conditions as they grow older.

This part of this Submission address a number of issues arising in the case of a relatively small number of individuals who find themselves at the interface of care provided under a CDIS (as per Part 1 of this submission) and the aged care system, particularly residential aged care. The total number of people at this interface in any one year is likely to be very small compared to the scale of the residential aged care system which has some 200,000 beds as of mid 2010. While most of those at the interface could be expected to be individuals who had been supported in the community by disability services, some may be individuals living in disability supported accommodation whose needs change in ways that make residential aged care more appropriate. Most will also have longstanding disability but others may experience the onset of disability in their late 50s or early 60s due to catastrophic injury, ageing related illness or worsening of other conditions with ageing.

The ways in which these interface issues are resolved have a number of consequences for the CDIS and other disability services and the aged care system. Positive resolution should facilitate access to the most appropriate care and inhibit inappropriate outcomes, but poor resolution could lead to perverse incentives and “pushing and shoving” between the two systems for individuals who do not fit easily into one or the other. It would be most regrettable to have these interface issues delay the introduction of a CDIS.

These comments are written more from the perspective of the aged care system than the disability services, and it is recognised that the issues look somewhat different depending on the perspective from which they are viewed.

2. Age as an eligibility criterion

How far decisions on eligibility for entry to a service system are determined by an age criterion or by individual assessment is determined in part by the number of individuals concerned and the variability of their circumstance. In the current case, the number of individuals is expected to be small, but they are likely to have widely differing needs. Individualized assessment is thus not only manageable but necessary on the grounds of those at the interface may in many ways be exceptions to the general rules governing the CDIS and aged care system.

Income support

The only area of Australian social policy in which an age criterion is strictly applied is income support. Recipients of Disability Support Pensions and other social security payments, including Carer Payment, transfer to the Age Pension on reaching the age of eligibility.

Carer Allowance

The Carer Allowance distinguishes between caring for a child (under age 16) and caring for an adult (age 16 and over).

Residential aged care

While age 70 and over is used as the basis for planning residential aged care services and community care packages, age *per se* is not a criterion for access to a place in a residential aged care home (RACH).

Disability services

Programs operating under the Commonwealth, State and Territory Disability Agreements (CSTDA) generally cover individuals entering the service system before age 65. Age 65 does not however appear to be strictly applied as a criterion for withdrawal of services when clients reach 65. (The gap between age 65 for CSTDA and 70 for the Commonwealth aged care programs raises the interesting question as how planning for those aged 65-70 is handled in both areas).

Home and Community Care Program (HACC)

The Home and Community Care Program covers all age groups. The wide coverage creates problems at the interface of both disability and aged care package programs. Paradoxically, the establishment of HACC occurred at the same time as nursing homes catering specifically for younger people were separated from aged care homes and transferred to the CSTDA, for example, nursing homes operated by the Australian Huntington's Disease Association.

Community Aged Care Package Programs

These programs are Community Aged Care Packages (CACPs), Extended Aged Care at Home packages (EACH) and Extended Aged Care at Home Dementia packages (EACH-D). Community care package programs are generally intended for those aged 70 and over as other State funded packages are available for younger clients (although insufficiently). Around 10% of all package recipients are under 70, but almost all are in the 60-70 age groups.

3. Scale of the interface

While imperfect indicators, the number of admission to RACH and the number of residents in RACH who are aged under 65 show that the scale of the interface is small compared to the scale of the aged care system. In 2007-08:

- 1,990 people aged under 65 were *admitted to* RACH in the year and they accounted for 3.7% of all admissions. Not all of these people would necessarily be covered by a future CDIS.
- There were 6,606 *residents* aged under 65 receiving permanent care (as opposed to respite care) and they accounted for 4.2% of all residents. Only 3% of these younger residents were aged under 40 (n=139) and 10% were aged 40-49; of the balance, 41% were aged 50-59 and almost half (46%) were 60-64.

- This figure compares with CSTDA accommodation services for 35,566 clients, of whom 5,059 were living in institutions/residential care settings and 11,414 in group homes; the other 19,714 received other forms of accommodation support, including support to remain in their existing home.
- The younger residents in RACH are different to the total resident population in a number of ways that point to their exceptional care needs:
    - In marked contrast to the total resident population, men accounted for the majority of these younger residents (55%), and the gender difference is more pronounced at the youngest ages (under 40).
    - Younger residents are more dependent than the total resident population, and this difference is again most pronounced at youngest ages. Compared to 50% of all residents in the two highest of the 8 dependency categories on the Resident Classification Scale then in use and 30% in the four lowest dependency categories, fully 81% of the under 40 group were in the two highest categories and only 7% in the four lowest, and for those aged 40-49, the proportions were 63% and 16% respectively. The 50-65 year age group were similar in dependency to the total resident population.
- Notwithstanding recent efforts to reduce the number of younger people living in RACH, allowing for growth of the population, the 6,606 younger residents in 2008 compares with 5,787 in 1998, when they accounted for 4.5% of all residents. Detailed age data for the under 65 group are not available for all years so it is not possible to establish whether a decline in the youngest age groups has been offset by an increase in those closer to 65.
- The rate at which people aged under 65 use residential aged care has remained stable at 0.4 per 1000 from 1998 to 2008. This stability contrasts with the decline of around 20% in rates of use of residential care across the 70-85 age groups and declines of around 15% for those aged 65-69 and 85 and over.
- Paradoxically, one of the factors contributing to this stability may be the substantial increase in the proportion of people with profound or severe activity limitations aged 5-64 who are living in the community rather than in cared accommodation (excluding disability group homes).
    - The number living in cared accommodation in 2003 was 11,000 lower than in 1981, a decline of 40%. This trend was most marked at younger ages, indicating that the trend is primarily due to avoidance of admission to care rather than deinstitutionalisation of those who have already been living in cared accommodation.
    - Thus, in the event that these individuals face increasing care needs, including the limited capacity of ageing carers to continue to high levels of support, they may access the aged care system whereas in earlier years they would have remained in their former supported accommodation.
    - Continuation of this trend to community living, possibly furthered under a CDIS in future, could see more ageing people with disability eventually seeking access to the aged care system.

- A full account of younger people in RACH and the outcomes of initiatives offering alternative accommodation to these existing residents and for others at risk of admission have been reported by AIHW (Cat. No. DIS 53, February 2009).

4. A “convergence” approach

Rather than adopting a single criterion of age of onset of disability under 65 for deciding who will be covered by the CDIS, an approach that provides for “convergence” with the aged care system is seen to offer advantages in ensuring that individuals receive the kinds of support that are most appropriate to the nature of their disability and its foreseeable course, their life course stage, and family and local community circumstances. Convergence could also have benefits for providers in terms of appropriate referrals of clients and funding commensurate with residents care needs.

Possibilities for convergence arise particularly in assessment and in funding.

4.1 Joint assessment by ACATs and disability services

Aged Care Assessment Teams currently see few clients aged under 70, and assessment of the changing needs of younger people with disabilities who are ageing and who are experiencing the onset of ageing-related conditions currently appears problematic. Best practice occurs where assessments are carried out jointly by disability services that have been supporting the client and an ACAT, but access to skilled disability assessment appears much more uneven than access to ACATs. The experience of the ACAT program suggests that the development of a network of disability assessment teams similar to ACATs should be an essential part of the CDIS.

It is recognised that some younger people with disabilities may experience the onset of ageing related conditions at a relatively young age. For those already living in supported accommodation, and supported by the CDIS, every effort should be made to provide appropriate support for them to remain in what is their own home for as long as possible. Transfer to an aged care home should only occur in the event that the individual can no longer be supported and appropriate care, such as a high level of skilled nursing care, can only be accessed in a residential aged care home. When such transfers occur, funding should be provided through the aged care program at the relevant level on the Aged Care Funding Instrument (the ACFI replaced the RCS from 2008).

A further reason for enabling transfers from disability accommodation to RACH is that continued support of one individual to a high level of care may not be compatible with the support of other younger residents who have very different care needs, and may also take up a places that could be made available to others whose needs can best be met in disability accommodation. The very short supply of disability accommodation now and for the foreseeable future requires that available places should be made available to those whose needs cannot be met in other settings, whereas RACH are more readily available and should be used where they are can provide the most appropriate care.

Funding options

Several options can be proposed for funding of care in RACH for people previously covered by CDIS.

a) Continued coverage by CDIS

Continued coverage by CDIS would be consistent with current provisions in the Aged Care Act 1997, Section 44-20, for the Commonwealth to recover the cost of care for compensable residents in RACH. The part of costs to be recovered from the individual and from the compensation payer depends on the settlement of the compensation claim, in particular whether the settlement took account of the cost of providing residential care, and the Secretary of the Department of Health and Ageing is able to make determinations on these matters. The CDIS could make general provision for the costs of residential care at the time individuals required admission and then meet the weekly accommodation charge and costs of care at the relevant level set by the Aged Care Funding Instrument.

CDIS funding for care might not however mean simply continuing funding at the level prior to admission to a RACH. The amount to be paid by CDIS might be calculated in two components:

- A convergence approach would require that funding for all those admitted to RACH are funded according to care needs in residential aged care settings as determined by the Aged Care Funding Instrument (ACFI).
- Supplementary funding above the highest level of ACFI funding for those with very high care needs and for items not routinely covered by ACFI funding, for example, items of high cost and individually tailored equipment. The structure of the ACFI is consistent with allowance for supplements.

This two component approach would have a number of advantages. Automatic funding of some or all CDIS clients at a rate above the highest funding on the ACFI could create upwards pressures on ACFI funding. The capacity of aged care providers to game on funding classifications should not be underestimated and the situation to be avoided in residential aged care is to have former CDIS clients with equivalent needs to aged care clients receiving additional funding above the ACFI simply because they were covered by the CDIS prior to admission. This approach could also pre-empt attempts to enrol clients under the CDIS just before they were admitted in order to gain additional funding.

b) Means testing of fees and charges in RACH

RACH residents with incomes and asset above the Age Pension means test limits are required to pay means tested accommodation charges and care fees in addition to the Standard Care Fee that is set as a proportion of the Age Pension. In the expectation that CDIS clients would be admitted to high care, accommodation charges would be imposed by way of weekly charges and not lump sum bonds, except for Extra Services high care RACH.

Several factors suggest that under a convergence approach, CDIS clients would not be affected by means testing:

- The great majority of CDIS clients are likely to be reliant on Centrelink income benefits.
- Few would have assets in excess of the means test limits, particularly when the individual's prior home is exempted if a carer continues to live in that home. This exemption could be extended to situations where any dependents continue to live in the prior home.
- RACH residents whose income and assets are below the means test limits are defined as 'Concessional residents' and the Commonwealth meets the accommodation charges for these residents. The CDIS would do so for CDIS clients, at the same rate of payment as for Concessional residents.
- For the very few CDIS clients ever likely to have income and/or assets above the means test limits, such as when a person without dependents continues to own, or sells, their prior home,

an exemption from income tested fees and charges could be supported on the grounds that these individuals have additional needs and should be able to use their own income to support their on-going contact with and activities in the community, beyond those usually available to residents of aged care homes.

- Any CDIS client wanting to enter an Extra Services high care RACH and with the means to do so would be able to make that choice and meet their accommodation costs above the Concessional resident rate paid by the CDIS.
- If the CDIS covers care fees and accommodation charges for all CDIS clients without means testing, two questions that remain are:

    - Should CDIS clients be required to pay the Standard Care Fee that is set as a proportion of the Age Pension, or payable from a Disability Support Pension for those under 65 in receipt of DSP? While a convergence approach suggests the answers to this question should be yes, the level of fees in accommodation funded under the CSTDA needs to be taken into account.
    - On reaching age 70, should funding for CDIS clients be transfer to the aged care program? A convergence approach suggests that the answer to this question is yes, with allowance for continued CDIS funding of any care supplements above the ACFI.

c) Joint funding by the CDIS and residential aged care budget

This option is similar to the above option, except that the ACFI component would be covered by the aged care budget and only the supplementary component would be covered by the CDIS.

The disadvantages of this option are that it is administratively complex for RACH operators and it could create perverse incentives for “skimping and skimming” on ACFI funding in order to claim supplementary CDIS funding.

d) Modify the AFCI

The ACFI is essentially a case mix system, based on close to 200,000 residents. A small number of CDIS funded individuals required funding above the highest level of the ACFI would be outliers and should be treated as such, that is, they would be trimmed from the data.

The option of modifying the ACFI to incorporate CDIS clients with exceptionally high care needs is not recommended. Provision for supplements to be paid by the CDIS is preferable.

5. Recognition as a Special Needs Group

The aged care system currently recognises a number of special needs groups: Indigenous Australians, people from culturally and linguistically diverse backgrounds, those living in rural and remote areas, veterans, financially disadvantaged individuals, people with dementia, and carers. Membership of one or other of the special needs groups does not of itself however confer any additional direct funding for care. The only additional payments made are:

- In the case of financially disadvantage, the Commonwealth makes additional payments for accommodation for Concessional Residents and care fees are limited to a set proportion of the Age Pension.

- Additional payments are made indirectly for those in some rural and remote areas by way of viability payments to RACH providers.

5.1 Identifiable groups at the interface

A range of data point to a number of separate groups of individuals at the interface of the disability and aged care systems. The question that arises is how many of them, and which groups, would come under the CDIS rather than the aged care system. Published data do not provide a clear picture of the prior circumstances of those admitted to RACH at younger ages, but the table set out below suggests that the nature of disability as well as age of onset needs to be considered. This schema highlights the groups at the interface whose care needs are currently met to varying degrees by disability and/or aged care services. The key questions are

- whether all those under 65 would be covered in future by a CDIS and
- whether any of those aged 65 and over would be covered.

Age of onset / Nature of disability	Under age 40 Younger	Age 40-65 Middle	Age 65 and over Older
Causes not related to ageing	Disability from birth or acquired from trauma **CDIS**	Trauma, neurological conditions etc **CDIS**	Trauma **CDIS**
Non-age related compounded by ageing related conditions	Not applicable	Ageing related conditions experienced earlier by people with disability. **CDIS or Aged Care?**	Ageing individuals with established disability **CDIS or Aged Care?**
Ageing-related conditions	Not applicable	Early stroke, early onset dementia etc **Aged Care**	Stroke, Dementia etc **Aged Care**

It is likely that almost all those aged under 40 have longstanding and severe disability acquired at an earlier age or from sudden trauma, and so could in future be covered by the CDIS. Far fewer of those close to age 65 would be covered as many of these individuals would have ageing related disability, with varying proportions of those in the middle age range. Many of those in the 55-65 age group currently in RACH have suffered severe disability as a result of ageing-related conditions such as major strokes or early onset dementia and have care needs beyond the limits of community care, even when substantial care is provided by family members for those who have close family.

Three particular groups illustrate the difficulty of using age alone as a criterion for coverage under the CDIS.

5.2 People with early onset dementia

The situation of those with early onset dementia requires special consideration due to the often atypical presentation of the illness, its uneven progress, the high care demands placed on families and the high likelihood of eventual admission to a RACH for respite care and then permanent care. While a CDIS has been seen to be a possible source of funding care for people with early onset dementia, most cases of dementia occur in those over age 80, so that “early” onset can mean age 65 and while the onset of dementia may occur at ages as young as 40 to 50, AIHW estimates indicate that only one in 200 cases occurs before age 65. Very few cases of early onset dementia would thus come under a CDIS with eligibility set at under age 65.

The expertise available to diagnose, assess and support individuals with early onset dementia is available in the aged care system. The support for dementia care has expanded considerably over the last 15 years, and Alzheimer’s Australia was instrumental in securing the funding for EACH packages specifically for those with dementia. EACH-D packages are seen to be particularly suited to supporting those with early onset dementia who are most likely to have family carers. While care packages can delay admission to RACH, particularly when combined with residential respite care, the eventual outcome for many users of EACH-D and other care packages is admission to permanent care.

Increasing support in future would arguably best be achieved by expanding the availability of EACH-D packages and more dementia-specific respite care in community and residential care settings. Use of respite care has been found to both delay admission to permanent care and to facilitate admission when it becomes necessary. Specialised dementia respite is available only in aged care services and further development of these services and other services for people with early onset dementia through the aged care program is a preferred option rather than seeking funding through the CDIS. Continued growth through the aged care program would also avoid competition for funding with other groups who have few if any other options and who are in greater needs of support through the CDIS.

5.3 Young-old people (~60-80) who acquire severe disabilities

Brain Injury Australia has identified the young-old as a group who are particularly at risk of falling between the stools of rehabilitation for working age people aimed at return to work, and rehabilitation provided to much older people through geriatric medical services. It is precisely their higher level of activity around the home and in recreation that places the young-old group at greater risk of severe, non-compensable injury.

Imposing an age limit of 65 for entry to the CDIS could exclude some in this group. Yet a fit 68 year old who suffered a spinal injury falling from a ladder while painting the house should arguably come under the CDIS in the first instance to obtain rehabilitation. Should this individual however come to need residential care due either to a poor outcome from rehabilitation or the onset of age-related conditions, s/he would transfer to the aged care system rather than receiving life-time care though the CDIS.

In 2003, the Commonwealth initiated the Aged Care Innovative Pool Disability Aged Care Program to provide community based aged care services to a limited number of younger people living in disability supported accommodation. Evaluation of the initiative found that it achieved its aims of avoiding or delaying admission to RACH, improving quality of life and identifying factors that contributed to premature entry to RACH.

5.4 Indigenous Australians

While the poorer health status and lower life expectancy of Indigenous Australians has been recognised in planning RACH for this population on the basis of age 50 and over, research is currently underway at Charles Darwin University to investigate whether this approach and provision of aged care services are the most appropriate way of addressing the care needs of late middle age Indigenous Australians with severe chronic illnesses and consequent disability.

It is pertinent to note that while the difference in life expectancy at birth between Indigenous and other Australians is 17 years, this gap narrows to 6 years for life expectancy at age 65. Rates of severe and profound disability among late middle aged Indigenous people (aged 55-64) are about double those of the rest of the population, indicating that Indigenous people in this age group may be more likely to be supported by the CDIS.

While the rates of use of residential aged care by Indigenous people under the age of 70 are much higher than for the non-Indigenous population, the absolute numbers are very small. Of some 1,000 Indigenous residents in RACH in 2008, only 10% were aged under 60, 20% were aged between 60 and 69 and fully 70% were aged 70 and over.

A high proportion of Indigenous residents are in RACH operated by Indigenous agencies in regional and remote areas. Many of these agencies deliver community care, including care packages, as well as RACH and as well as having developed considerable expertise, they have strong community connections. The complex health and care needs of ageing Indigenous people with high levels of disability, and the particular configurations of services in the communities in which many live, mean that very particular consideration would need to be given to how each individual’s needs can best be met as they grow older. Further responses might best be pursued through Multi-Purpose Services and Flexible Care Packages that have been shown to achieve positive outcomes.

6. Note on international experience

A number of long term care insurance systems in other countries cover all age groups, but some cover only older people or ageing-related conditions among those aged 40 and older.

Japan’s long term care insurance scheme covers “ageing-related conditions” rather than defining eligibility on the basis of age. By implication, the CDIS could cater for disability that was not related to ageing, regardless of the age of onset of disability, with the aged care system covering ageing-related disability, again regardless of age of onset.

The Israeli system covered women from age 60 and men from age 65. Younger age groups are covered by other long term care insurance programs.

The German and Austrian systems cover all age groups, but the proportion of clients aged under 60 or 65 is small. The following figures are from the mid to late 1990s, but are illustrative:

- In the Austrian scheme, 17% were aged under 60: 3% were aged 0-20, 5% were 21-40 and 9% were 41-60.

- In the German scheme, 22% were aged under 65: 4% were aged 0-14, 2% were 15-24, and 16% were 25-64.

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Statistical data mentioned in this submission are taken from AIHW sources unless otherwise indicated.