

The inquiry to develop a Long-Term Care and Support Scheme is indeed most welcome. I fully support the establishment of such a scheme and propose to comment mainly on the key issue of how to build a good system recognising that there are many issues and inefficiencies in the current system.

My comments are made on the basis of an extensive commercial career before assuming the role of CEO of a large disability organisation some four years ago. In the varied commercial roles I have undertaken three of these were as the chief strategist for major Australian corporations. I mention the latter roles because it has been my experience that there is often a tendency when looking strategically at major issues such as this proposed new scheme that much of the focus will be on detailing individual issues and perhaps more micro issues, which are certainly very important for the Commission to understand. The Commission in its Issues Paper has already acknowledged that there is a huge body of evidence demonstrating the great unmet demand of this sector, the inequity of benefits allocated and the significant funding required enabling people to have a better life and allowing them to make choices.

The Commission's Issues Paper (May 2010) summarises the concerns that people with a disability have with the current system. Underlying those issues is a fundamental issue which unless adequately addressed will not result in a cost effective system delivering quality services. It is true that there are a multitude of questions to be answered and those of eligibility; coverage; choice; governance and replacement of existing funding are important issues.

But in my view the fundamental issue is the need for important structural reform of the current disability delivery system. This is the core design issue which needs to be addressed so that watershed new scheme can deliver to its potential.

Both in the Issues Paper and submissions received to date, there is one theme seemingly very difficult for both State and Federal Governments to appreciate. That is the fragmented and un-coordinated approach in servicing the needs of the disabled community in Australia. I would say "un-coordinated" is probably the best description. Despite the fact that 1 in 20 Australians have a disability<sup>1</sup> Government departments are not structured for success in dealing with the disability sector. Each Department has addressed the needs of this community by seemingly tacking on disability programs onto their existing departmental programs. This in itself is not a criticism. But what eventuates is an un-coordinated approach overall to providing service. The experience that people encounter when trying to resolve their individual issues is the need to access small parts of the overall solution by dealing with multiple departments, who

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<sup>1</sup> ABS 2003

may have differing policies, inconsistent interpretations and a whole raft of bureaucratic processes. It's like putting together a jigsaw puzzle.

There is no **one** department or program that deals with their issues and thus we are forcing people who are already very stressed to establish multiple contacts and wade through complex and very challenging paperwork, bureaucratic procedures and differing policies.

Such a process is also extremely inefficient and does not deliver value for money and given funding will be a major concern for a new scheme this is a critical concern for the success of the scheme. Your terms of reference seek input about funding but the underlying issue is can the level of funding be significantly reduced by ensuring efficiency in delivery systems? I think so and therefore will enhance the acceptance by Australians of the scheme.

Let me provide an example of this inefficiency. A typical example is that of a person with a spinal cord injury that requires several items of equipment to be able to move around; a wheelchair; commode for the toilet; a bed; home modifications following the injury; or needs to source different accessible accommodation; modify or purchase a vehicle; apply for the appropriate financial benefits; and importantly securing the necessary care package. A significant number of new requirements in order to maintain an existing environment and preferably remain at home and if possible go to work.

These fundamental and critical elements of personal care, housing and equipment are handled by different Government departments and they act in an un-coordinated manner because they were established and organised to service a different community. Able bodied people may require several services supplied by Government departments at different times and are capable of negotiating the labyrinth of processes to achieve an outcome. But a disabled person who is under stress needs to have a packaged solution, one which considers their individual choices and provides the mechanism for delivery, both for current needs and over the longer term.

The number of contacts required to secure an outcome is further complicated by differing policies and budgets across departments and dealing with staffs of these departments who may have had no face to face contact with people with a disability and all too often treat them as mere statistics.

A more general example I heard recently was of a wife and mother of five children, two of whom have a disability. She and her husband are under considerable stress. The home environment is generally frantic and approaching breaking point as both she and her husband, primary carers, are under continual stress, have not had a real break in some time and economically are finding everyday existence difficult. After many telephone calls in dealing with the current daunting system she is fortunate to make

contact with someone helpful and knowledgeable, someone who understands her requirements. But then she is presented with a list of telephone contacts for her to personally pursue. This is the silliness of the existing system! She has presented to the system as someone in need and the help she receives, and she is one of the lucky ones, is a list of telephone numbers which she has to wade through with invariably very mixed results.

It seems where there is better coordination is in exiting people from hospital. In these cases the incentive to free up beds seems to create a greater impetus for action and coordination. Yet even in these cases there are delays in sourcing equipment and if someone needs a power wheel chair they will not be funded for a manual wheelchair, which is necessary in some transport situations.

I am certain there will be many submissions with more detailed descriptions of inadequacies in the current system and my point to the Commission is therefore that an important structural change should occur to eliminate the jurisdictional issues and inefficiencies brought about by lack of coordination and the authority to implement.

Some suggestions that could be considered are;

- The establishment of a key new Federal Government body whose function is to provide quality service outcomes to the disability sector. This new body, perhaps an independent statutory body, or Ministry, to be the only national body Australia wide with no other separate State ministries only branches of the national body in each State. Its funding base to come from the existing State budgets proportionately allocated as it relates to identified disability funding from Health, Ageing, Housing, Transport, Disability and Education etc. In addition, the new NDIS scheme would have developed a funding stream(s) that would augment this budget from some form of levy and in the initial years provide for the target population eligible for this scheme (discussed further on in the submission).
- The importance in founding such a body is that it can deliver a standardised and equitable service to all Australians no matter where they are, reduce the paperwork and red tape, and increase efficiency. The establishment of uniform policy, regulation and governance is critical and will always be problematic as long as there are individual State bodies involved without an over arching controller.
- Another critical component of this new body is the front line staff. These “front of house” officers of the new body, let’s call them “advisors”<sup>2</sup> would determine with the “client” their life cycle requirements and either by telephone contact or more

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<sup>2</sup> An alternate name could be ‘Case manager’ but to the physical disabled community this implies intellectual disability and is therefore not favoured.

desirably by a personal visit, clearly document both **current** and likely **future** demands for care, service, and equipment. This aspect is critical as demand for services for each individual will increase over time<sup>3</sup>.

- Having established a client's demand requirements, the Advisor now has the authority, across multiple Ministries/departments to implement a solution recognising that each Advisor will have a budget allocation to work within that has been centrally considered and approved. This is no different to how most commercial and government departments work today except that the significant difference is the ability to implement across existing departments.
- The cost effectiveness of such a program lies in removing many layers of bureaucracy and also engaging directly with the client as to choice of solution. Thus defining "person centered" and other terms is really irrelevant as the client is at the centre of determining service delivery and more importantly has on hand an Advisor (or facilitator) to implement the desired solution with full knowledge of budget and implementation issues.
- Having a key structure in place is perhaps the most important consideration of the scheme with the next levels being to determine who is eligible and how the scheme can be funded. This is addressed by commenting on the Commissions questions below.

Addressing some of the Commission's questions:

**1. Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.**

Both Victoria and NSW operate a motor accident scheme taking the "no fault" approach. Both schemes have shown that reducing the cost of litigation and directing those funds into a pool have removed the necessity to establishing who is at fault and thus contributing to a timely support outcome for those in need.

An essential element of the proposed scheme must be a "no fault" approach.

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<sup>3</sup> This seems incomprehensible in many programs and since requirements are usually unchanged for many years the tendency is to go for the maximum support because that is all that will be delivered. Clearly there are budget reasons for this inflexibility

## **2. The Commission is to consider the following specific design issues of any proposed scheme:**

- **eligibility criteria for the scheme, including appropriate age limits, assessment and review processes**

Whilst there are some 20% of the Australian population with a disability<sup>4</sup> not all of these people require an intervention or specialist support. Currently it is estimated that some 750,000 people aged under 65 have a severe or profound disability. Less than **one third** of these people currently receive support so it should be a priority to extend support to those most in need in the severe and profound category in the initial implementation of the scheme. With an appropriate assessment process in place these people can be identified.

In later stages, once a number of teething issues have been sorted out and the financial stability of the scheme established, the target population should be extended.

An important point to note and a significant fault in the current support services is that the level of support requirements change over time but the support system applies a level of service which is difficult if not impossible to change with these increased demands. Hence the assessment and review process is an important element in the design of the scheme and also needs to identify at the initial assessment stage the likely growth in support over time. This is a critical budgetary element to ensure adequate support.

Currently the establishment of an age limit seems arbitrary. Governments are encouraging people to stay longer in the workplace, generally the population is living longer, yet somehow a static age limit seems to apply? Appreciating that there is a significant cost to a new system, in the initial period it is not unreasonable to adhere to the current general age for eligibility to be 65 but the system design should accept that over the longer term, all people with a disability, regardless of when the disability was acquired or their age should be entitled to support under the proposed new system.

- **coverage and entitlements (benefits)**

Having established an assessment process and say defined the entitled population as being those with severe and profound disabilities in the early years of the scheme, the entitlements need to be comprehensive and address total life cycle needs. For many people with a spinal cord injury this will involve high levels of equipment, perhaps up to 6 items (electric wheelchair; manual wheelchair; hoist; electric bed; commode chair etc). Currently funding only provides for a limited number of equipment items and this issue is further exacerbated by the fact that a person's needs will change over time.

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<sup>4</sup> 2003 ABS statistics

The importance of assessing a person's life cycle requirements cannot be over emphasised as this is critical both for the person and for budgetary purposes.

- **the choice of care providers including from the public, private and not-for-profit sectors**

The most important aspect for the providers of support services is that they should be quality assured. For such a system to be in place requires appropriate funding to the services providers and a governance structure that involves all the stakeholders and critically the client. An appropriate governance structure also needs an effective compliance and appeal system so that overall providers can undertake a continuous improvement approach.

A key question is the long term involvement of Government in the provision of services and also being the regulator. A personal view is that Government should retain the important role of regulator and policy formation but retreat from service provision that can be more cost effectively delivered by the not-for-profit sector. The utilisation of the private sector needs to be carefully managed.

- **contribution of, and impact on, informal care**

A significant contribution is being made by carers<sup>5</sup> who need to be better supported. The care they provide directly benefits all Australians. Many carers truly sacrifice their lives for the benefit of loved ones and not only do they need acknowledgment for their significant contribution but also attention needs to be paid to their wellbeing. The most obvious help a new scheme can provide to carers is access to respite services. If a significant portion of the informal care currently being delivered were withdrawn the burden to Australians would be enormous. Hence a prudent aspect of the scheme would be to ensure the continuity and wellbeing of this critical resource by providing at least appropriate respite care for the disabled.

- **the implications for the health and aged care systems**

Just as there is a need to review the current age threshold for disability benefits an urgent review is required as to why a person with a disability should not be entitled to long term support and at 65 needs to migrate into another category (Aged Care). People with a disability are living longer and this fact needs to be recognised in two ways. Firstly, their needs will change over time due to their disability and secondly, needs may be augmented by the fact that they are ageing.

In a similar vein the new scheme should only provide incremental costs to that normally incurred in normal day to day living (i.e. assist in the incremental costs that arise as a result of a person's disability). A person with a disability should be entitled to any benefit or support that an ageing person would be entitled to.

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<sup>5</sup> ABS 2004, Disability, Ageing and Carers, ABS, Canberra, pp33 & 54

- **the interaction with, or inclusion of, employment services and income support**

It is impossible to consider the employment issue without also raising the need for adequate transport options and accessibility. Whether or not a person is employable is academic if they cannot get to work and if having overcome that obstacle the workplace is not suitably accessible. These are two very important issues that have still not been adequately addressed. As with accommodation issues, Australia still needs to embrace the universal design rules for accommodation and buildings and not make this a matter of choice or self regulation.

The other two issues regarding employment are the uninformed attitude of employers to people with a disability and the lack of appropriate incentives both from the employee and employer perspective.

Attitudes to employing people with a disability will only change once education and “good news” stories are published to demonstrate to employers that they are benefitting from employing people who have a well established reputation for punctuality, loyalty and quality of work over able bodied persons.

On the other hand, incentives to employees need to be provided to ensure they are motivated to leave their homes and re-enter the community and contribute to it. Having people on disability support programs which are not in themselves providing significant financial support and penalising them when small amounts of additional income are earned does not encourage participation.

Further incentives for employers to be considered are both the removal of complex and bureaucratic paperwork when employing a person with a disability and providing financial incentive. An able bodied employee does not undergo the degree of reporting and “case management” that employers are obliged to undertake when employing a person with a disability and hence a disincentive is created. The amount of paperwork and auditing that is undertaken is absurd and from my experience does not result in any improvement in outcomes.

- **where appropriate, the interaction with: national and state-based traumatic injury schemes, with particular consideration of the implications for existing compensation arrangements**

Clearly the two States that currently have a “no fault” scheme in place have much to contribute to the Commission in lessons learnt.

### **3. Consider governance and administrative arrangements for any proposed scheme including:**

- **the governance model for overseeing a scheme and prudential arrangements**

For the scheme to succeed it would need to have a national consistency and entitlement. Irrespective of where the person lives, the scheme should strive to deliver consistent quality outcomes. For this reason I can only envisage as suggested at the outset a new Ministry/Statutory Body with State based branch offices overseeing the scheme and auditing its implementation.

- **administrative arrangements, including consideration of national, state and/or regional administrative models**

Critical to this scheme is the incorporation of equity for regional areas. All too often there are issues with providing care in regional areas because of the lack of support workers. In some cases, in order to provide adequate support, a worker may need to travel considerable distances and the current system does not adequately provide for these additional costs. Once again, at the assessment stage it should be clearly identified what the cost and support implications are for an individual and plans established to deliver this level of care over the long term. Having one Ministry responsible seems a necessary requirement for success.

- **implications for Commonwealth and State and Territory responsibilities**

No doubt there will be considerable change at both Federal and State levels if a new Australian body is formed to administer this scheme. As with all change it will depend on how well the program is introduced to the various levels and the demonstration of the benefits to those departments and how they could become more efficient. The loss of some portion of budget may be cited as a concern but the reality is that whatever budget was formerly allocated to the disability sector was never sufficient so one would hope that reasonable managements would recognise the advantages of a centralised approach and more appropriate funding for the target population.

- **appeal and review processes for scheme claimants and participants.**

A qualified initial assessment process is critical coupled with an appropriate governance structure. This will then enable a formal review to be undertaken with the client and also provide a basis for settling disputes which will inevitably arise. The review process itself needs to be conducted at differing intervals depending on the disability but more generally should not exceed two years. There have been cases for instance where people have not had a review of their equipment requirements for many years. Three respondents to a recent survey indicated their last reviews were in 1987, 1989 and 1995 respectively. One may well ask



how this could be and the answer could be as simple as they were not aware of their entitlements.

A formal assessment and review process for all participants in the scheme should address these types of issues.

#### **4. Consider costs and financing of any proposed scheme.**

This complex area can best be addressed when an estimate is made of what the target population will be and what structure the scheme will embrace. As the current population of severe and profoundly disabled persons is not being adequately addressed, the first step would be to understand the cost implications of servicing this population for their total life cycle costs. They will inevitably be huge.

The next step would be to do the “gap analysis” and assuming that budgets will be carved out from other Ministries, determine the gap funding that is required and anticipate that Australians will be prepared to support some additional levy to provide for their fellow citizens, especially if it can be demonstrated that bureaucracies at State level have been made more effective and that direct personal advice is being provided to scheme participants with more timely implementation over the longer term.

The Commission needs to appreciate the point that for this sector, individual requirements change over time, there is nothing static about the level of care required and hence the fundamental system design needs to recognise this important aspect and provide the essential budget to implement.

In short, once the target population is identified/defined and an agreed structure developed to deliver quality services the necessary funding can be determined.

#### **5. Consider implementation issues of any proposed scheme.**

- **changes that would be required to existing service systems**

One significant issue for the new scheme is the lack of data across Australia on the need for disability services. As an example, recently statistics were sought to determine the population distribution of people with a spinal cord injury to better determine the unmet need for supported accommodation. This is a classic case where family members invariably are supporting someone with a spinal cord injury and are concerned with their ongoing support once they die. The Commission will no doubt receive many submissions along a similar vein as

there is insufficient supported accommodation being constructed or supported by Government<sup>6</sup>.

In pure strategic language terms *“if you don’t know where you’re going, any road will take you there!”* seems to appropriately sum up the situation with data. How planning for services can be formulated with the paucity of data currently available is a mystery. Yet this data although not entirely accurate is available within various departments. Eligibility for benefits would be one source of data that could be used to put together a comprehensive data bank together with other sources as to how many and where people with various disabilities are located.

There needs to be a better gathering of data also from the ABS perspective and it would be helpful if the one reason so often cited for not doing anything, “privacy”, could be rationally applied. In short while there are departments with relevant data they don’t liaise sufficiently and hence as mentioned at outset of this submission, there is a need for a national body to both administer and manage the new scheme.

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<sup>6</sup> Given the paucity of such supported accommodation there is usually only one alternative and that is an aged care facility which is not appropriate for this population as they have particular issues not addressed by these facilities.