Thank you for the opportunity to contribute to this review.

For the past one year my sister has been taking care of our mother at home, as well as her husband for the past seven years. Both have disabilities due to brain damage and both are elderly.

An EACH package is provided for Mum and a CACPs package for my brother in law.

My sister continues in her employment as she

- does not wish to resort to welfare support even though there would be no difference financially,
- makes a contribution to society through her work, and
- finds that the stimulation of a work environment is respite in the caring role.

I work and live in Sydney and travel to Tasmania for four days each month, to assist my sister with care. This has not been easy as I was recently diagnosed with a serious illness and will continue to receive treatment over the next one year.
However we are both committed to care for the family and wish to prevent Mum's institutionalisation.

Since Mum's illness last year we have had experiences with the aged care system that have been positive, surprising, and disappointing. In this submission we have addressed our concerns against the issues identified by the Productivity Commission.

Are the aged care services that older Australians require available and accessible? Are there gaps that result in a loss of continuity of care?

A gap that we experience is that of safe and appropriate respite services. We have twice accessed residential respite for Mum. On both occasions she was not well cared for, but instead neglected. We believe that contributory factors are low staffing, poor skills, and low standards.
Mum's mobility is limited so that she needs someone with her holding her safety belt whilst she walks with a frame. In both facilities she was kept wheelchair bound and received no exercise at all, certainly no physio. She required double her usual (twice weekly) physio for one month to restore her pre-respite function.
In respite Mum was placed in a low care section in both facilities despite her high care needs. The skills of staff were limited such that in one facility when her bladder catheter fell out because the bag was not drained, the nurse simply re-inserted the same catheter. The result was an extremely severe infection.

Consumer-managed respite whereby the funds are managed through Medicare rebates would be a more desirable option.
This would enable the recipient and carer the option of self managing respite so that it is tailored to needs.
For example a choice of overnight in-home respite may pose less risk of disorientation or care deficit, and less deconditioning of the recipient, but might expend a proportionately higher amount of respite. For the gains in quality of care, the reduced hours can be a worthwhile trade-off, that a consumer may choose.

Is there sufficient emphasis within the current system on maintaining a person's independence and on health promotion and rehabilitation? How might any inadequacies in the system be addressed?

Delivery of the EACH Package

We have found that the EACH package is not used to support or enable rehabilitation or restoration. A restorative approach is an area about which we feel qualified to comment. We are both registered nurses, my sister in the aged care sector (APS) and I in acute care. We specifically wished for Mum to receive complex care at home to maximise her recovery potential. In one year with physiotherapy twice per week at a clinic and daily at home Mum has progressed from immobility in a tilt-in-space wheelchair to walking short distances (about 30 metres) in a small rollator frame, and to transfer from bed to chair.

Mum was unable to swallow adequately and we resisted relentless pressure to have a PEG tube inserted for feeding. Instead we persevered with Mum's nutritional rehab at home and she has now progressed to swallowing a normal diet with the exception of such foods as crackers.

There is provision in the package for some allied health – We suspect that this is seldom provided. If the provision of packages was monitored and the care planning process required the use of professionals, then the lack of a rehabilitative or health maintenance approach may become visible and require redress.

Equipment

The provider has not supplied any equipment, and in fact only agreed to deliver the package if we would agree to forgo their responsibility to provide equipment. This has included a height adjustable bed, wheelchair, shower chair, commode, manual handling belts, rollator frame. We have also supplied an exercise bike and adjustable chair which would not be required from the package provider.

There is provision in the package for equipment. If the delivery of packages was monitored and the care planning process identified equipment needs, then failure to supply this should be identified.

Training of care workers

Providers seem not to employ carers with appropriate qualifications for complex care – some have no qualifications or experience at all. There are no requirements set down for this.

There have been instances of poor manual handling by carers and when we alerted the provider to our concerns it was not rectified. We subsequently arranged and paid for staff training in manual handling techniques by Mum's physio and we manage the skill maintenance ourselves.

Cognitively Mum has improved somewhat but suffers from mood swings so her behaviour fluctuates, and she has some cognitive impairment due to the trauma. We found that the carers are not trained in responding to behaviour difficulties, even though they are caring for people on EACH-D packages.

It may be that the vocational training courses do not adequately prepare workers for complex care provision in community settings.

Supervision of carers is absent, and although a nurse/case manager is employed, carers are not observed in practice. This is commonly the case.

There should be a minimum standard of qualification vered by unregulated workers in an unsupervised environment such as people's homes. There should also be competence assessment dependent upon the needs of the client, so that no client is subject to the risks associated with poor hygiene, poor manual handling and so on, as has been our experience.

We have devised strategies and plans to assist the carers and Mum when the difficulties arise, however there is no doubt that carers are poorly equipped to provide care to people with complex care needs. We have since spoken with other primary carers who have had similar experiences although we are aware of two providers in the locality who do employ skilled and qualified workers.

The primary carer is generally left to identify learning needs and skill deficits that are then required to be reported to the nurse/case manager.
Assessment and care planning is sometimes not undertaken by nurses, but instead by workers who are not qualified to undertake such tasks.
The care plan is not reviewed and in Mum's case this has caused us many problems as it is quite inaccurate.
There is a need for standards regarding education and skill levels of nurses and carers. There do not seem to be accountability requirements of nurses in this setting, so staff are generally not guided, supported, trained or supervised.

How well does the aged care system interface with the wider health and social services sectors?
We found that hospital personnel had a poor understanding of the scope of the complex care package and tended to think it applied to people with low care needs.
The view expressed to us by hospital personnel and by providers was that people with complex care needs should be institutionalised.
This view is so pervasive that

- ACAT assessments are tailored accordingly;
- package providers seem to avoid accepting clients with actual complex care needs (eg catheter, reduced or no mobility, cognitive impairments, self care deficits).
- the knowledge and skills of carers, nurses is too limited for the provision of safe care.
- Access to complex care packages is hindered so that lower care needs clients receive priority.
- Providers tend to dissuade primary carers delivering complex care from accessing community based care, instead referring them to institutional services. Consumers and primary carers who resist are often described as unrealistic or even …'dysfunctional' regardless of the family commitment and the articulated wishes of the care recipient.

Should there be greater emphasis on consumer-directed care in the delivery of services, and would this enable more older Australians to exercise their preference to live independently in their own homes for longer with appropriate care and support?
The recent announcement of the so-called consumer directed care packages is misleading. Under this model the care is really determined and directed by providers,

- Providers have been assigned packages regardless of their track record.
- Consumers are selected for the packages by the providers.

- Providers can still retain a large percentage of the package for their (redundant) 'case management and administration', and still charge consumers additional fees.
- There is nothing to prevent the same problems from recurring.

We realise that only about 40% of the value of the CACP package is delivered to my brother in law and about 48% of the value of the EACH package is delivered to my mother. Given that we are paying for training of care workers, equipment, physiotherapy, podiatry, allied health assessments and that we have had to prepare our own procedure information sheets, and care plans, this percentage of delivery is very unfair. We are paying for case management and skills that are not delivered.

There is a great very real need to provide a package option whereby the consumer (or primary carer) can administer the package in order to maximise its' efficiency. It could possibly be operated through Medicare with rebates and should be subject to quality and prudential testing in the same way as approved providers.

Packages need to be delivered so that they are a genuine alternative to institutionalisation. Currently there seems to be a widely held view that packages are a part of a continuum of care which inevitably ends in an institution. The notion that complex care cannot be delivered in a community setting is a myth. There are many younger people living in the community who have complex and significant needs due to chronic disease and disabilities.
Another example of complex care at home is that of community based palliative care. In fact we believe that recipients can be safer in community care than in an institution.

People with special needs
There are many aged people with a disability and the experience of my sister with regard to her husband's care is that the transition from access to disability services to that of aged care services has been enlightening and difficult. The ability of aged services to understand and meet the needs of a person with a disability is very limited. There is a comparatively poor skill base combined with a paternalistic approach to aged care service provision that is an unacceptable approach in disability care.

Who should pay for aged care services? Are the current government subsidies and user charges for aged care appropriate? Are there components of aged care costs — accommodation, living expenses, personal and health care — that warrant government subsidies and/or should they be the personal responsibility of older Australians? To what extent should means testing be applied?
Current subsidies may be adequate. Our calculation of services to my mother and to my brother in law is that less than half of the value of both packages are delivered in our family. The first step is to do with assuring the probity of the providers. It may be that further requirements regarding the direct care expenditure level is considered. User charges on EACH and EACHD can be quite a drain, particularly when one is trying to pay for physio, equipment, and other aspects that should be enforceable as package needs. The risk is security of tenure for the client though, so one is at risk if one complains.

How might the public and private exposure to the financial risks associated with aged care costs be best managed?

We think that the preparedness and motivation of primary carers to care for a person at home should be recognised. Where it is possible the primary carer should be allowed to case manage and these savings should be able to be invested back into direct care.

How important is the provision of choice for older people requiring care? Are there components of aged care which older people value choice more highly than others? Is there any evidence which suggests that the provision of greater choice may have resource implications? Should subsidies that 'follow' approved clients be paid to providers directly or should care consumers be given the choice of receiving such payments first to promote a greater capacity to exercise choice?

We believe that consumer choice could result in more efficient use of package funds. For example my mother could receive appropriate rehabilitation so that her mobility could improve further. This is likely to result in less care requirement in the medium term.

The provision of appropriate equipment is likely to save care delivery time and create a safer environment for care workers and us.

The provision of adequate care and support will enable my sister to remain in the workforce for longer.

Informed choice is essential and requires an accountability mechanism to be established for example as My Aged Care (such as My Hospital or My School). This would mean that providers complaints history, ACFI history, breaches of the Aged Care Act, would be on the public record.

Are current subsidies sufficient to provide adequate levels of care? What are the minimum benchmark levels of care in each of the service areas and how should they be adjusted over time to meet changing expectations?

Community care subsidies are likely to be adequate, however the performance indicators monitoring data collected by DoHA are quite flawed with many unaccounted for variables. One good example is that of direct care, which is poorly defined and is able to capture all types of administrative time and costs.

What impact does the regulation and its enforcement have on older people, their carers (including access to, and quality of, care) and providers (including their business models and size of their operations)?

Unfortunately in the community based package programs there is no engagement of consumers in evaluation or review of services (for example through the Quality Review process).

Some providers survey consumers but regardless of the survey return rate (which may be as low as one response only), the result is nationally benchmarked as a 100% return. Consequently the results (which are ostensibly the consumer input into the process) are quite skewed.

We have been surveyed, but the comments we made were not included in our provider's survey results.

There is no connection between the Quality Review program and consumers. This should be a face to face process without the provider present.

There is no accreditation role in community care.
There are significant discrepancies between the Accreditation Agency findings in Tasmania and the reality in aged care facilities, having used several aged care facilities for respite between our two family members.
The introduction to community programs of the ACFI monitoring system may be of benefit in minimising the so-called 'cherry-picking' by providers in respect to accepting the most desirable clients (ie those with the least needs).
The focus on profit (euphemistically called surpluses) in community care is a significant impediment to the proper use of these packages.
The transfer of HACC program to the Commonwealth will provide the suite of low, medium and complex care required. At present CACPs are treated as low care and EACH and EACH D are treated as medium care. This means that limited care/services are delivered (in comparison to DoHA criteria for their provision) so profits are maximised, consumers are bluffed into using residential care when that has not been their preference, and staff are poorly trained and ill-equipped for their roles.

Are the rights of aged care consumers adequately protected and understood?
Security of tenure in community care environment is fragile with a tenuous provision in the Payment Agreement, variously interpreted.
Consumers are very vulnerable in community settings. We have felt threatened by the provider's implications that the care is beyond their capability (because they do not wish to invest more than about 50% of the value of the package) and are aware of others similarly at risk.
We now have fully brokered personal care services, primarily due to the skill deficits of the approved providers' team. We are now not constantly confronted with the inadequacies of an ill-prepared provider. The care provision is now of an acceptable standard, however there seems little logic in limiting the potential of this package by adding 30% on-costs in brokerage, purely because the provider has limitations in their ability to adequately deliver.

Are complaint and redress mechanisms accessible, sufficient and appropriate for all parties?
We, (like most of our fellow carers) would not risk the package by making a complaint.
We are aware of the mechanisms for making a complaint.
The Complaint Scheme should be separate from the Department of Health and Ageing (which is both the funder and the regulator of aged care).

What specific regulatory reforms could address the concerns listed above? How would the reforms improve outcomes for users and providers of aged care services while maintaining appropriate control of quality and safety?

- Strengthen security of tenure for community care and flexible care packages to equate with that of residential care.
- Assess potential providers capability and capacity to deliver packages – quality assurance before the inception of packages, not left until three years after their inception.
- Introduce consumer input into Quality Review directly with the Department of Health & Ageing not filtered by a third party. This should be using consumer panels and consumer meetings whereby the reviewers actually meet the recipient of care.

- ACFI funding and funding audits of community care and flexible care packages, along with an internal comparative review of ACAT assessment findings.
- Consumer managed care packages, not via an approved provider.
- Limit brokerage potential by providers to specialist services (physiotherapy, nutrition assessment, Occupational therapy, diversional therapy planning, continence management) to maximise the direct care potential of the package.
- Competence requirements of staff and associated provider responsibilities along with regulated care workers.
- A dependency based staffing system, based upon ACFI dependency measures to assure a minimum standard of skill mix and staffing numbers.

Where multiple regulatory instruments are seen as requiring joint reform, which reforms should take priority? What scope is there to reduce duplicative regulations (for example, the dual gatekeeping mechanisms imposed by the ACAT assessment and the allocation/planning system)?

ACFI funding in residential aged care is inconsistent with ACAT instrument and the result is often that the care classification is incongruent. For example a client may be assessed at low care by ACAT but found to be high care under ACFI following admission to an aged care facility as a low care recipient (or vice versa). There is an opportunity for one instrument to be used.

Will the announced changes in government roles and responsibilities benefit aged care users and improve the administration of the aged care system?

HACC

What issues remain to be addressed? Should there be further reforms to the way in which the system is administered? What are the net benefits that such reforms might deliver?

Brokerage of services by package providers should be curtailed to specialist services. The confusion regarding accountabilities and responsibilities is unacceptable as is the significant additional expenditure, preventing value for moneys

What are the key issues concerning the current formal aged care workforce, including remuneration and retention, and the attractiveness of the aged care environment relative to the broader health and community care sector?

Training
Acceptable service standards
A workforce dependency model that ensures a minimum standard of care and safety.
Nurse practitioners
Scholarships for professional development (eg palliative care, wound management etc)

Are there unexploited productivity and efficiency gains in the aged care sector? Where such unexploited gains are seen to exist, what policy changes are needed to support their realisation?

The application of ACFI to the community care environment.