Thank you for the opportunity to contribute to the discussion about this reform.

The Explanatory Memorandum for the Aged Care (Living Longer Living Better) Bill 2013 addresses a number of the Human Rights strengths of the Bill however it does not address existing inequities even where they are a potential impediment to these reforms.
In particular the Living Longer Living Better Bill does not address a common problem whereby approved providers prejudice access to their services and consumers have no redress.

This practice by providers is commonly known in the sector as 'cherry picking' whereby those clients who represent best value to an aged care business will have priority of access to care. They tend to exclude those with equipment needs, those with supervision needs, those whose needs require specifically skilled staff, and informed consumers who may place 'greater demands' upon a service to deliver as required.

Since the change to the Aged Care Funding Instrument (ACFI) for example many approved providers (of residential care) have escalated their exclusionary practices by selecting clients who will place the least demand on their package or their residential place and have removed specifically skilled service delivery staff (such as physiotherapists, occupational therapists, diversional therapists and nursing professionals).

For some providers this depletion of care and service provision is congruent with growth in business management resources – such as expenditure of Commonwealth subsidies for care on ACFI consultants, information specialties, and finance. At the same time care workers are proportionally low in number as the service delivery component of the business.

The legislation as proposed will still enable aged care business operators to be protected from scrutiny in a system that, for consumers, is complicated, does not promote its' user rights widely, and will serve an ever increasing number of cognitively impaired consumers who will ultimately lack the capacity to communicate or seek redress of wrongs.

There are some services that are not addressed in this Bill such as Home and Community Care (HACC) funded services and National Respite for Carers (NRCP) funded services. HACC services are often referred to as 'low care' services.

This is a specious definition as HACC services often have conditions of allocation that enable complex or complementary support to clients with high level needs (such as through dementia-specific day centres, chronic wound management clinics, palliative nursing, meals, transport).

However, whilst this inaccuracy exists, unscrupulous aged care providers are permitted to continue to exclude those with higher level needs. My own experience in this regard has been that the consumer has no recourse through the only departmental avenue of the Complaint Scheme.

I live in Tasmania where to my knowledge the majority of aged care services are delivered by the non-government sector who receive subsidy funding from the Commonwealth government.
My experience is as primary carer of my husband (since 2003) and my mother (since 2009). They both have dementia and my husband also has a range of limitations due to a traumatic brain injury. I feel qualified to speak about a range of services, in particular

1. Community based packaged care
2. Day centres – dementia specific, compared with day centres for people with brain injuries.
3. Residential respite compared with cottage respite
4. Dementia Behaviour Management Advisory Service (DBMAS).

I take care of both family members at home with the support of community programs and it is my intention that they will remain at home with me for the remainder of their lives. The service we receive through the EACH D package for my mother is excellent. We have been awaiting an EACH D package for my husband for 17 months now.

I work 22.5 hours per week. Unfortunately it is not possible for me to work longer hours due to the requirements of Centrelink and the lack of access to dementia-specific day centre services.

My husband is affected by his brain injury and now dementia. He experiences planning and executive functional losses so

- he cannot cross a road without supervision,
- he cannot use a telephone,
- he rarely is able to dress himself without assistance and prompting,
- he requires prompting for toileting and personal care, to get drinks, to eat, and to sit.

My husband suffers from mood swings. He is unable to make financial decisions or health care decisions. If he is left alone in an environment other than our home he becomes lost.

My mother has dementia as the result of a brain haemorrhage in 2009. Her condition is advanced and she has a range of functional losses caused by the progression of her dementia. These include inability to walk, inability to speak, and swallowing limitations so that her diet is modified. Mum is unable perform any activities of daily living. Nor is she able to interact in a social environment, however because I care for her I know when she is happy and engaged. My mother loves music, painting, and children. We take her to a local park in her wheelchair and she very much enjoys watching children play. She attends weekly physiotherapy and this helps to maintain some limb mobility.

I would like to give you three examples of my experiences where I have tried to use appropriate channels to obtain redress to no avail because there is no provision within the Aged Care Act (1997) or relevant guidelines.

Respite
I have not had respite for my mother for 15 months.
Each time respite is booked by the Commonwealth Care Link and Respite Centre it is cancelled by the residential care provider for the reason that my mother's needs are too great. I have tried the available avenues for redress but there is no recourse under the Aged Care Act 1997 for denial of access to services.
The alternative available is access to a consumer-directed respite package which could be applied to overnight respite at home for a few nights each year. These packages are only available in my city through the same organisation that operates the Commonwealth Care Link and Respite Centre (CCRC). The CCRC decides the assignment of a package (or even a portion of a package) on the basis

of their view of the care burden. Apparently my care burden is not sufficient to warrant support so I cannot access a package, or even a portion of a package. This decision is despite the refusal of residential services to accept my mother for respite. I have no recourse. The consumer directed respite packages have no requirement for equitable distribution, there is no monitoring or accountability requirement in respect to identified need or priority.

Day Centres

After my husband had been attending a HACC funded day centre (for the aged) in Hobart for approximately 3 years there was a change of manager. At that time I was informed that my husband could not continue to attend this day centre due to his incontinence and his need to be regularly prompted to toilet. My husband has suffered incontinence and urge incontinence since his brain injury in 2003. The HACC Guidelines do not prevent exclusion on the basis of physical limitations or illnesses and I have been told that he was only permitted to attend the day centre for the first three years because of the interpretation of the Guidelines by that manager.

So again I have no redress in terms of his access to HACC funded day centres because although he has a condition that many people suffer as they age, it is not one that is tolerated by some approved providers.

My mother has this year been required to leave one of the only two dementia-specific day centres (again HACC funded) in Hobart. The reason given was that, as a recipient of packaged care (EACH D), she is not eligible to receive HACC funded day centre services.

The HACC Guidelines specify that a person is not ineligible for a service that cannot be provided through packaged care (such as a day centre). My mother benefited very much from the social environment and group involvement of a day centre. I therefore requested that she be allowed to attend without any care being provided (feeding, drinks, personal care) and I would ensure that these needs were met prior to and following her (4 hours) attendance. This the approved provider refused. She is unable to attend the remaining day centre as they also do not allow access by people in wheelchairs.

In addition to refusing my mother access the provider has stipulated fees for people on packaged care that are quadruple the fee for other clients, and without any transport support making it completely unaffordable.

Apparently this is common and ensures that the service is able to 'cherry pick' clients with the least needs and most money, irrespective that the day centre is identified departmentally as 'dementia specific'.

The funder (Department of Health and Ageing) cannot assist us as they have said that the HACC guidelines are unclear except to say that my mother is 'not ineligible' for the service. HACC is not included under the Aged Care Act, so there are no legislated requirements. The Guidelines are deliberately vague and infer that people with 'low care' needs have priority.

Again there is no remedy open to me.

These decisions by aged care providers

1. have affected the quality of life of both my mother and my husband
2. are a direct result of our choice to use community care rather than institutional residential care
3. have detrimentally affected my ability to attend my employment;
4. should be viewed as examples of this sector where there are many providers who actively seek to exclude people with needs so as to maximise their profit margin (or 'surplus' as it is euphemistically known)

5. exemplify the risk to the many more people using packaged care who will be forced into permanent institutional care due to a lack of community services to support such needs as psychosocial well being when their condition progresses.

Day centre services are almost inevitably HACC funded, however HACC is not subject to the Aged Care Act 1997.
The aged care industry has many providers who have no intention of providing services to people as their dementia progresses, or alternatively will only cater for one symptom of dementia (such as wandering which affects only 5% of sufferers and does not remain the sole symptom).
It has become an industry and it is focused on revenues and competition for profit, regardless of non government or charitable status – both of which are poorly understood, but are advantageous for the providers.

I believe that the Department of Health and Ageing has a strong bias toward the services that they both fund and regulate.
It should be patently obvious that it is inappropriate that the funder should operate this ultimate avenue for consumer redress (the Complaint Scheme), which incidentally, has been reviewed and modified to its present impotent state by the funder.

My own experience of the Complaint Scheme is that it has been rendered so powerless (since the Walton Review) that it now has neither the ability or will to challenge unfairness or to redress the inappropriate use of funds (such as denying access to dementia-specific support services in the growing sector of community care).

I am committed to caring for my mother and my husband and have tried very hard to resolve these problems but they cannot be solved. This is because of the partiality toward providers through the current inadequate legislation and guidelines, deficits in the conditions of funding allocations, and abrogation responsibility for ensuring that such requirements and conditions are met.

Nor are these problems redressed by legislation of the Living Longer Living Better Bills as proposed; instead they will be exacerbated if the Bills are not amended to address equitable service access throughout the aged care sector.

I would like the following matters to be considered in amending the Bills to address equity and access:

Defined conditions of funding allocation that will prevent unreasonable exclusion of clients and promote access aligned with the intent of the Living Longer living Better policy framework. This could include the development, application to all existing aged care services, and monitoring of priority of access criteria that are relevant to the Commonwealth funding purpose and conditions.

Monitoring of the approved provider's equity of access and adequacy of service provision claims against the needs of home care clients, and where relevant, primary carers (as per the intent of the current ACFI system in use in residential aged care). This should be applicable to all services who receive funding to provide aged care services (including those such as HACC and NRCP that are currently not subject to the Aged Care Act 1997).