I was thrilled when I heard details of the Productivity Commission's proposed disability reforms on ABC radio - which were mentioned in relation to an upcoming conference later in May 2011 on 'Communities in Control' (i.e. empowering the care recipient and care provider to make the choice as to how funds would be best expended). I was further buoyed when I subsequently read the Productivity Commission's key features paper (Feb 2011) – especially where it states, in the overview, that the National Disability Insurance Scheme "would be like Medicare, in that all Australians with a significant disability would get long term care and support". However, it was not until I sought clarification, that reality set in - and I checked the terms of reference.

Of course not all Australians will qualify for the proposed National Disability Insurance Scheme. Only those who are under age pension age, or have a significant disability that is not aged related will qualify. Although it is virtually impossible to come up with a clear definition of what constitutes 'age related', it is evident that people with dementia or arthritis – such as my partner and myself - can expect to be excluded.

Some of us, who have been caring for our loved ones for years, have been desperately waiting for much-needed disability care reforms – along the lines of those proposed in the Disability Care and Support draft. It is devastating to learn that we will likely be excluded – particularly because the exact same criticisms and complaints that have given rise to the proposed NDIS equally apply to carers of care recipients over age pension age. However, we will be forced to continue with the 'we know best' inefficient system of self-serving government funded care providers - or continue to go without assistance. We will doubtless continue with the latter.

It is obviously through no fault of the Productivity Commission, that an age restriction has been imposed in the terms of reference, but age is not a disease or a disability or a diagnosis and I suspect it may be impossible to determine whether the disability of a person over 65 is due to a catastrophic injury (such as a TBI) or their 'age related' failure to recover (because their age precluded treatment). It begs the question how such a determination will be made, and whether we will see doctors 'assisting' patients to qualify for NIIS in preference to a possible different/inferior level of care and support under existing aged care arrangements.

In reality there is probably no longer such a thing as an age related disability – and certainly not at age pension age. Life expectancies have significantly increased in line with our improved health as we age. Today's 65 year old is generally much fitter than a 65 year old of fifty years ago (who was probably physically and mentally more the equivalent of today's 85 year old). Recognition that we are healthier and more capable of continuing to work at a much older age is reflected in the government's increasing entry age for eligibility to age pension. This is further reflected in the fact that the age set for eligibility for ACAT assessments is 70, with statistics confirming that admission to an aged care facility is unlikely to occur until age 85.

Sadly there are already too many seemingly arbitrary age criterion used to determine eligibility for, or exclusion from, services (and the criterion seems to have more to do with money that need). I am disappointed that the peak body which purports to advocate for all people with dementia, Alzheimer's Australia, does not appear to have even presented a submission to the Productivity Commission regarding 'Disability Care and Support' for those with dementia – and especially those with early onset dementia.

Dementia is not a disease of ageing – it is not even a disease, it is a condition, which simply means loss of cognitive function. It may be temporary or permanent, and may be preventable or curable. It can also be the result of catastrophic events such as a fall or collision, and it can be a consequence of medical negligence or malpractice. As we get much older, i.e. 85, the risk of developing neurodegenerative dementia increases, and even after that age senile dementia

remains highly unlikely. Dementia onset before age 80 is generally not age related, but often linked to other contributory causes – such as genetics or inappropriate neurotoxic medications.

It is also well recognised that 'falls with head injuries' is a significant risk factor for neurodegenerative dementias, and a significant number of people who have suffered TBI's – and especially those who have been inappropriately or inadequately treated or medicated – have subsequently gone on to develop dementia. But it seems unlikely that such people would qualify under the NIIS scheme.

I am carer for my partner who developed early signs of (possibly inherited) dementia at age 63 – which could also have been due to inappropriate medication. However, she subsequently suffered a significant TBI, which led to her being forced to cease work at 67. She was too young to qualify for assessment from ACAT (with an age criterion of 70) and too old to qualify for Headwest (with an age criterion of under 65). As a consequence, she was neither appropriately diagnosed nor treated until the damage was irreparable. As an author and publisher, she could have continued to work well into her 80's - had she not become mentally disabled. Her disability is not due to her age, but to her circumstances. If the tables had been turned and, as a 55 year old, it had been my arthritis that had deteriorated into a significant disability, my partner would have presumably been able to obtain assistance under the NDIS at least until I turned 65.

It has been our experience that the 'one size fits all' method of assessment, as used by HACC aged care providers (for services and respite), doesn't fit – and we have found it necessary to strike out ourselves and seek out appropriate services and assistance within the community. Being effectively forced to pay the (unsubsidised) market rate, for services that do suit us, means we cannot afford as much assistance as would otherwise be available through a government subsidised HACC provider e.g. under an EACH or EACHD package.

It is of note that, with regard to aged care reform, the 'we know best' government funded (vested interest) service providers appear to have successfully lobbied the government (and the Productivity Commission) to maintain the status quo and, in the process, to ignore the wishes of carers and care recipients (who these government funded HACC providers purported to represent). By default, carers and recipients of age care services - who actually sought a funding model similar to that proposed for the younger disability sector - have been ignored by both the peak bodies who purport to represent them and the Productivity Commission, which heavily relied upon the submissions of those peak bodies.

It seems that the Productivity Commission's proposed 'aged care' reforms will actually be to the distinct detriment of people such as us, whereas the Productivity Commission's 'disability care' reforms - which would have enabled people such as us to access significant assistance - are to be denied us. Carers and care recipients, such as ourselves, will be forced to continue to tread our own path, and be denied fair and reasonable access to government funding.

In a country with probably the healthiest economy, and the youngest population of any developed economy, it is not our ageing population that we should be concerned about, so much as our ageist population. Can anybody imagine the reaction if the Productivity Commission had been asked to exclude disabled people on the basis of gender or race, instead of age?

It is to be hoped that, before the Productivity Commission's age and disability reforms are adopted by government, common sense will prevail and the proposed discriminatory distinction between disabled people either side of 65 will be removed.

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