Caring for older Australians Inquiry – Public Hearing, Perth WA Friday 1 April 2011. Submission by Angela Smith, North Beach WA (representative of the silent majority of informal at-home carers and care recipients)

1. The Productivity Commission has received, and seemingly taken into consideration, submissions from vested interest groups who receive government funding to provide aged care - either in institutions or in the community. The Commission has also presumably taken into consideration the views of some groups who purport to speak for grass roots members. However, having read much of your January 2011 Draft Report[1], I am not convinced that you (or they) have widely consulted with or taken into consideration the views or concerns of the silent majority – those of us who are informal at-home carers and care recipients – and who will eventually decide whether your proposed reforms are sufficiently 'fair and reasonable' to elect any government that contemplates adopting your recommendations.

2. While members of the Aged Care Alliance have made it clear they hope the government adopts your recommendations in its entirety, I - and others - hope that the government sees your report for what it is, and suggests you adopt the views and recommendations of a more representative mix of relevant contributors (such as us). I thank the Commission for the opportunity to contribute prior to the submission of your Final Report to parliament.

3. I initially became involved in social welfare, and particularly in relation to older Australians, in the mid to late 1970's. I was subsequently across a number of reviews, seminars and papers concerning the care of the aged in WA.[2,3,4,5] On 8/6/1986 Jennifer Page (from QEII Medical Centre) presented a paper for the Bureau for the Aged concerning the development of policy for the aged. She began her paper with the caution "Many people do not study history in relation to their particular field of work. Knowledge of history of policy for the elderly is critical in understanding present policies, programs and practices and their tenacity in a climate for change."

4. Put frankly, if you don't know your history you can't learn from it and you set yourself up to repeat the mistakes of the past. Based on my reading of your Draft Report, I am not convinced that you have undertaken an extensive examination of Australia's aged care history and, that being the case, you are set to repeat some of the mistakes made – or averted - in the past.

5. I was WA's Publicity Officer when the Hawke Labor government introduced the Pensions Income & Assets Test, and well recall the basis for the exclusion of the family home as an asset – but you, and those who weren't involved, appear to have ignored that part of history.

6. I was similarly involved in the combined state and federal government rollout of the home and community care program (HACC) - and was dumbfounded when, a couple of decades later, I approached my local council for assistance and was advised that there wasn't any money for any services to people in our predicament (and we live in the council area with the highest number of older persons in this state).

7. It seems to me that vested interest groups have hijacked the initial concept of HACC. Just because something is (or purports to be) 'not for profit', does not mean it is more productive or for the betterment of the community. And outsourcing essential human services, such as aged care, to the lowest bidder – as appears to have occurred in our increasingly ageist and selfish society - has shown itself to be a recipe for disaster.

8. I don't believe anybody is arguing that the current aged care system is not in crisis – but there is much disagreement as to the causes, and how to fix it.

9. I am currently speaking as 'minder' for my partner who was last year diagnosed with a terminal illness – Alzheimer's type dementia. She began to experience memory problems more than ten years ago and sought medical advice but a series of tests were unremarkable. She was - at the time - taking a number of prescribed and over the counter medications that have subsequently been linked to cognitive impairment.

10. Her condition took a marked turn for the worse after a traumatic brain injury (TBI) seven years ago. Following intervention by a psychiatrist (and the cessation of those contraindicated medications) her condition noticeably improved, and it has only very slowly deteriorated in the past 18 months. Obviously she does not - as yet - require high care, but presumably could do so in the next five to fifteen years. In the meantime I will do everything within my power to ensure that she does not end up in a nursing home (despite an almost total lack of support from organisations who are being funded to assist the likes of us).

    N.B You will note that I refer to institutions who provide high care as 'nursing homes' – because I am concerned that the change in nomenclature to 'aged care' facilities (and your proposal to remove the distinction between low and high care funding models) is a consequence of a deliberate attempt by vested interest groups to manipulate community perceptions, and to downplay the need for quality geriatric nursing and medical care to people who are severely disabled.

11. The slowed rate of my partner's decline, and the concomitant extent of her care needs, is almost certainly linked to her stress levels – not least because chronic stress is known to affect the hippocampus - the region often initially adversely affected by Alzheimer's. The fact that my partner's condition has deteriorated only very slowly is almost certainly because I ceased full time work three and a half years ago, so that I could especially ensure that her stress levels were kept to a minimum.

12. In so doing, however, I have personally undergone a substantial financial loss and an enormous increase in my own stress levels. I can certainly understand why the carers of people with dementia have a reduced life expectancy of ten years, and a seven-fold increase in the risk of developing dementia themselves. However, what I never anticipated was that the majority of my stress wouldn't come from my caring role per se, but from my seemingly relentless battles with 'unhelpful' bureaucracies (government and non government).

13. I have been left shattered at the level of the vilification I have received from those I expected would be supportive of our choice (family, medical and financial professionals, bureaucrats and 'decision making' authorities). It is as though anybody with dementia – or any other increasingly debilitating condition - should be promptly written off, denied any chance of any quality of life, and banged up in a nursing home death camp at the earliest opportunity.

14. My stress levels, and likely financial ruin, have been unquestionably exacerbated - not simply by the lack of support or recognition that my contribution has substantially alleviated our care burden on the taxpayer - but by a relentless assault on me personally. Nobody, it seems, can believe that anybody does anything out of love and compassion anymore, so I must have an ulterior motive, and I must be treated worse than a criminal.

15. Our predicament has probably been exacerbated because we are a same sex couple with a significant age difference (and people cannot resist making their own value judgements), but

it could equally apply to the many LATs (living apart together) heterosexual couples who have chosen such a lifestyle in order to avoid the vagaries of the Family Court. Your proposed draft 'reforms' fail to recognise the disparate relationships in a modern society, and seem to place far too high a reliance on a one-size-fits-all model of a traditional relationship – which especially adversely impacts on the likes of us (be that deliberate or unintentional).

16. After commencing my caring journey, I joined the National Consumer Dementia Research Network (CDRN) and Alzheimer's WA, Carers WA, COTA WA and National Seniors WA in the misguided expectation that they would provide advice, support and guidance. With the exception of the first mentioned group, I would have to say that I have been disappointed.

17. I have repeatedly encountered a lack of assistance and advocacy from bureaucracies (government and non-government) - and have been in repeated contact with MPs, Health and Ageing Ministers, Attorney Generals, and 'so called' support groups such as Advocare. I have become a regular reader and contributor of letters to *The West Australian* newspaper – as well as *The Senior* and *Have A Go News*.

18. Having more than fifteen years in the social welfare field (in WA, SA and Canberra) and subsequently retraining as a research and analytical scientist, before I became a full time carer, I am not ignorant or talking out of context – and yet I have been accused of such. With my background, I expected I would have a greater knowledge than the average person about the benefits and services available - or would at least know how to go about finding out what assistance is available.

19. To say that I have been vocal in my touting for a fair go for people in our situation would be an understatement. And yet, while I was embroiled in endless battles with those who were failing to assist us, I had no idea that a Productivity Commission was undertaking a review into aged care – of either institutions, or the home and community care program.

20. The first I heard of your review was in January 2011 when I read a press release from Alzheimer's Australia (through the National CDRN - and not Alzheimer's WA), closely followed by an article in *The West Australian* newspaper, and an article in the February 2011 issue of *The Senior* - which attributed Anne-Marie Archer as **the** spokesperson of the 'peak' body on aged care issues in WA.

21. Everybody, or so it seemed to me, was claiming that 'views had been widely canvassed', and that your proposed changes were 'carefully considered' and deemed 'fair and reasonable' – except, from my perspective, they seemed anything but. I subsequently read a number of submissions to your Productivity Commission review into aged care - and especially from those groups who purport to speak for the likes of us – and it seemed blindingly obvious that none of them were speaking for us.

22. I was forced to ask myself, if they were not speaking for us then why were they not speaking for me? And if they were not speaking for us then who were they speaking for? And if they weren't speaking for us was anybody? It is apparent to me that your report is biased toward the views of vested interest groups – those who make a living from providing aged care services (both private and not-for-profit groups).

23. As I have already mentioned, Anne Marie Archer, CEO of Aged Care Association WA (who is a journalist by training) is very adept at getting the perspective of her private enterprise members brought to the forefront. Stephen Kobelke, CEO of Aged & Community Services

WA, similarly attempts to lay claim that he is spokesperson for the not-for-profit peak body in WA.

24. Of course both are keen to encourage ‘all Australians to be united in the push for changes’ - which suit their members. However, neither speaks for the overwhelming majority of disabled older people who happen to live in their own homes in the community – and not in their aged care facilities (be they not-for-profit or profit based). Unfortunately, even the Chief Executive of National Seniors, Michael O’Neill, didn’t appear to have widely consulted with his members - until he became aware of a backlash following the January 2011 release of your Draft Report.

25. What I have difficulty understanding is how you could expect your proposals to be accepted by a government that hopes to get elected – especially as the 50 plus vote is not insignificant. Did you not consider the outcome of the Henry Review of Taxation? Those in that inner sanctum were similarly full of self-adulation, and suggested the review be adopted in its entirety – but what happened? Too late, it seems, somebody eventually got the message that the emperor had no clothes.

26. Sadly, after all the time and money spent on your Aged Care review, the same propaganda appears to have been trotted out – and especially by an ‘Aged Care Alliance’ of vested interest groups who appear to have whitewashed the history of aged care in this country, and who arrogantly plead that the government not ‘cherry pick’ your recommendations. I too hope the government doesn’t cherry pick your recommendations. I hope your report gets rewritten in its entirety before it gets submitted to the government, because what you are proposing in your Draft Report will not fix the aged care crisis – it will likely make it worse.

27. If you have not already done so, I suggest you carefully consider the responses from the ‘non-peak’ bodies who provided comments - as summarised in the March 2011 issue of *The Senior* newspaper. Groups like: Agedcarecrisis; the Combined Pensioners & Superannuants Association; The Retirement Village Residents Association, and; the Elder Abuse Prevention Agency. They appear to be speaking for the little people - people like us.

28. You begin your report by promulgating the scaremongering of a projected tsunami of elderly that is going to bear down upon us and swamp us in forty years time. It may surprise you but, had you carefully considered the demographics for yourselves, you might well conclude that such predictions are grossly pessimistic – and crystal ball gazing at best.

29. Humans have studied population demographics, and made adjustments, for generations. In fact the Australian government introduced a levy to pay for our aged care pensions in 1956 (55 years ago) but at some stage it was quietly absorbed into general revenue. If that levy had been kept separate, it would have paid for the care needs of current and future older Australians. Of course that money has never been repaid, and it is effectively still there, except the government has reallocated it to more pressing priorities like winning cricket matches and Olympic gold medals and paying baby bonuses or commissioning submarines and destroyers that sit idle because they don’t have enough crew.

30. Despite your dire projections, I can see no tangible evidence to substantiate such pessimistic claims. What I could not initially understand was why your Draft Report appeared to be so blatantly ageist and shamelessly discriminating against older disabled people? You appear to echoing the nonsense parroted by younger generations that older Australians are responsible for this country’s economic ills, and that it is ‘fair and equitable’ for people over 65 to make

an even greater contribution than they have already made (which is far more than younger Australians are likely to ever contribute).

31. To try and make direct correlations between today's 85 year olds with those turning 85 in forty years time is like comparing apples with gum nuts, and you cannot hope to draw comparisons or extrapolate from such disparate groups.

32. Today's 85 year old was born in 1925 i.e. they were born in the depression and grew up during World War 2. They did it tough and they went without. Many lost husbands, fathers and breadwinners or other loved ones during that war. Some of today's 85 year olds even fought in the latter years of that war. Women left at home alone were forced to fill in for menfolk who were enlisted, and when the war ended those women – who had just experienced their first (and mostly only) taste of non-subservience - were the first to be demobbed and sent back to be housewives.

33. Our governments then deliberately swelled our population with migrants and refugees (many non English speaking) who came from far and wide - and all were encouraged to have lots of kids. Most weren't wealthy; many came on assisted passages - and the menfolk took on dirty and dangerous jobs in mines (including asbestos) or building dams or irrigation schemes or other infrastructure.

34. There wasn't much in the way of health and safety in workplaces back then. In fact, many of today's 85 year olds need high care in nursing homes because of conditions that are the result of past unsafe (work or medical) practices. The use of early versions of pain relievers, such as aspirin and paracetamol, was widespread (with many taking a Bex a day) – until a link between liver and kidney disease was disclosed in the 1970s.

35. There is now a suggested strong link between regular use of such pain relievers and Alzheimer's – a disease that was not even identified until 20 years after those drugs went on the mass market.[6] Suffice to say, it is entirely possible that future generations (who haven't taken those drugs) might not have the same incidence of Alzheimer's – but you won't hear that from vested interest groups.

36. Today's 85 year old's didn't have the contraceptive pill or maternity allowance or child care allowance; the women stayed at home and looked after the children and, because many were migrants, they had no extended family to help out. The family lived off one wage, and they went without until they could save up for something. They rented out modest (3 bedroom one bathroom) state housing commission houses – which many later bought (and many still live in unimproved). Some went on to fight in the Korean War and in the Vietnam War.

37. After looking after their own children, the older women were called upon to help look after their grandchildren. Many of them also looked after their own aged parents or disabled siblings. Of course many of these women knew little other than caring roles, because they were forced to resign from work if they married (plus many of their husbands forbade them from working).

38. They also grew up being respectful of older people and considerate of those less fortunate. In addition to their unpaid caring contributions, Australia's older men and women - after reaching compulsory retirement age, or being forced out early due to ill health – contributed countless thousands of hours in volunteer work through hospitals, schools, fire fighting, sporting and community work. Their direct tax contribution may have waned but they contributed to the productivity of this country in other ways.

39. There was no superannuation for most of their working lives and, even when it was introduced, they were forced to pay into their employers' chosen fund – and to pay multiple administration fees if they had more than one job. Many lost entire nest eggs to rogue traders who were allowed into the marketplace by inadequate legislation enacted by incompetent governments. Even Britain's Jeffery Archer recently discovered that government's taxing of superannuation had resulted in 40 % of his nest egg being – as he so eloquently put it - "stolen at source". He called it pernicious theft by any standards – and suggested to future generations "don't bother."

40. My own accountant and I (and untold others) could have told Jeffrey Archer that twenty years ago but, like Jeffrey Archer, we have all been forced to throw away our precious savings to these greed mongers. In my own experience, one of the biggest offenders was GESB, the now privatised state government employees' super fund who, in one year alone, 'stole' more than 80% of my contributions. Legislation has apparently been drafted to prevent future occurrences of such trickery, but it does nothing to recoup any of my 'stolen' nest egg.

41. Most 85 year old's are by no means rich and, for many, their modest home is their only asset. It is all they have as a fall back (reverse mortgage) for unforseen expenses - and it is the only asset they hoped to pass on to their children or chosen beneficiaries. Many have already been persuaded to transfer ownership to children before they move to nursing homes or die – in return for life tenure. How many more will do so in order to avoid your suggestion that they sell their home to pay for a couple of years of palliative nursing home care at the end of their life? Will you be placing caveats on properties where reverse mortgages are not an option, or will you exempt such 'evaders' from payment of a bond?

42. Despite their decades of tax and informal 'contributions' (via incalculable hours in voluntary work), you have the temerity to suggest that it is 'fair and reasonable' for frugal elderly homeowners to pay still more for their nursing home care. Of course you have proposed that if there is still a partner, then that partner will be allowed to remain in the family home – but you are making generalised assumptions about the financial and personal arrangements of disparate 'couples'. Will you place a stipulation on whether the home must be in joint names, or how long the couple must have lived together in the home, or the age disparity of the partners?

43. It is not unusual for older men (particularly) to remarry and to younger women. What if an 80 year old marries a 40 year old? Will the home still be exempt for the term of the younger partner's natural life? And if so will that not invite 'evasion'? If that older man has moved in to his younger wife's home, do you expect a reverse mortgage to be taken out over his new 'home' (which he doesn't own) or the home of his former wife – which is in his name but is occupied by his former wife who was given life tenure in a settlement agreement. Does one or both women get to remain in their respective homes until he has departed the mortal coil?

44. We already have students moving in and providing companionship and odd jobs in return for a mention in an older person's Will. Have you anticipated taking such long-standing agreements into consideration?

45. We additionally have some baby boomer retirees unashamedly asserting that they intend to spend their kids inheritance, and to be the poorest person in the cemetery – leaving barely enough for their funerals. Are you considering forcing them to set aside an amount for their late life care? Will you place caveats on their property assets?

46. No matter how much Anne-Marie Archer or Stephen Kobelke (or spruikers like Alannah MacTeirnan) attempt to dupe the general public, nursing home care for severely disabled people is not the same as accommodation in their own homes. Nursing home care for chronically disabled older people is no different to any other form of nursing or hospital or palliative care for any other age group.

47. Prior to the establishment of purpose built nursing homes, older disabled people were 'accommodated' in the geriatric wards of public hospitals. They were not seen as bed blockers because those wards, and staff, were as much an integral part of the hospital as the maternity ward.

48. High care nursing home accommodation is tantamount to palliative care for chronically ill people who are in the end stages of life. It is not a bloody holiday camp where you might choose a glass of wine with your tea. Moving into nursing home high care is rarely a choice; it is forced on severely disabled people who cannot get an adequate level of care in their own home (and not least because HACC assistance is woefully inadequate to non-existent).

49. Many same sex, and some heterosexual couples, have separate financial and living arrangements LATS – Living Apart Together Sexually (or socially). Nowhere in your report can I see consideration of anything other than a conventional shared home/shared financial arrangement of a one-man/one-woman married couple of similar age, and from a life long relationship.

50. In today's society it is increasingly acknowledged that "when you have seen one you have seen one" – precious few scenarios are the same. If your Draft Reforms are adopted, without taking into consideration the disparity among us, half the population could end up falling through the obvious cracks.

51. For people with dementia – like my partner – all the medical research asserts that the best possible place for her is in the familiarity of her own home; a home that she has lived in for more than forty years. The only way that she could continue to live in her home was for me to move in with her and to cease work to care for her. Her Doctor effectively made that decision for us by insisting it was imperative I cease work and provide the care –and not some paid stranger. However, such a sacrifice also necessitated selling my own home, because – without an income - I could not meet the mortgage payments on my property.

52. My savings are consequently being progressively depleted in order to provide the services we need but cannot get from a seemingly non-existent HACC program. My name is not on the title of 'our home', and consequently - if your proposed 'fair and reasonable' reforms get through - people in my situation will become homeless, because our 'homes' would have to be sold to pay for our partners high care (possibly only for a few weeks or months at the end of their life).

53. We also have to contend with the possibility that the Family Court could deem us 'separated' and order the sale of our home to pay for nursing home fees anyway (if some interfering busybody decided my partner must be moved to a nursing home because I was 'unsuited' to providing appropriate care).

54. Alannah MacTeirnan (*The West Australian*, p 18, 28/2/11 – copy attached) erroneously suggested, "For those who want to keep the asset, reverse mortgages can provide the bond which is eventually later paid out from the estate." Such as flippant dismissal ignores the

fact that many, like us, have already been forced to take out reverse mortgages to cover everyday living expenses – having been stripped of life savings through federal government mismanagement of the superannuation scheme (and having to pay exorbitant utility costs, thanks to incompetent State governments).

55. Alannah also derisively suggested those of us who oppose the selling of the family home are “hysterical” and ‘polarising debate to protect the inheritance of their children’ – which in our case is garbage because neither of us have any children. However, Alannah had already pointed out in that same article “When they shuffle off the mortal coil, their estate gets the money back – minus a modest annual deduction.”

56. So Alannah et al thinks it is apparently ‘reasonable’ that I must expect to be made homeless, because our ‘home’ needs to be used as collateral to provide high care for a few months - but that is okay, because I will get most of it refunded after my partner has died. How absurd.

57. That anybody should be expected to pay hundreds of thousands of dollars up front - only to have it repaid to the estate after they have ‘shuffled off the mortal coil’ is usury. If there has to be any contribution, why not pay as you go? Why are people being asked to provide loans to money-grubbing private industries? It is an aberration for the likes of Alannah MacTeirnan, Anne-Marie Archer or Stephen Kobelke to try and dismiss the concerns of those directly involved as ‘out of context’ or ‘hysterical’ or motivated by ‘greed’.

58. From my perspective, the current demands from nursing homes amounts to blackmail. ‘Give us an extortionate amount of money – far more than it will cost to provide the service – and we will deign to repay what is left of it after you are dead.’ Can you imagine the outcry if private schools were to try that on with parents of prospective students: “The annual fees are $12,000 but we want you to pay $70,000 up front so we can put some of it toward a new library. We will deduct the fees over the duration of your child’s stay – and when he/she leaves we will refund your balance from fees we have extorted from other parents.” Of course parents would go elsewhere – unless, like all nursing homes, all schools had formed a cartel and were all making the same demands.

59. Your suggested commandeering of the family home to pay for aged care accommodation, is yet another attempt at ‘pernicious theft’. There will be no need for anybody to concern themselves with death taxes, because you will have stripped us of our assets before we die – which bears a frightening resemblance to what the Nazi’s did to its ‘unproductive’ physically and mentally disabled at the start of the holocaust. Or did you not know about that little bit of history either. In a cash-strapped post World War I Germany, Hitler convinced the struggling populace that it would be humane to euthanize the severely physically and mentally disabled being kept alive in institutions.

60. What I also cannot understand is why are you suggesting that there will be an increased aged care ‘burden’ in 40 years time, when there is a plethora of evidence to suggest that today’s 45 year olds will be self funded retirees and nowhere near as disabled as their counterparts of today. Plus, you seem to have overlooked that fact that the vast majority of us will have been persuaded to sign ‘not for resuscitation’ Advanced Health Directives – or have practiced voluntary euthanasia (whether it is legal or not)?

61. My comparison of today’s 85 year old’s with those who will be 85 year old in forty years time (2050) – someone who is now 45 and was born in 1970 – paints a different picture to your unsubstantiated predictions.

62. Today's 45 year old's grew up with contraception, and were encouraged to have small families. Many have wanted for nothing, and grown up in double income households. They spent much of their own adulthood in double income (sometimes LATS) partnerships. Today's 45-year-old women benefitted from the feminist struggles of their mothers, Aunts and grandmothers.

63. Many are university qualified, and were able to defer starting a family or choosing not to have a family (because they could) until after they had a career and a house or two. Those who delayed having children until their late thirties or early forties have increased health risks, and incurred more expensive medical procedures associated with that decision. They have more premature babies and caesareans. Are you going to suggest they should be asked to mortgage or sell their home to pay for their (self inflicted) increased financial health care 'burden' on the taxpayer? Or is it just older Australians that are being singled out for unfair treatment?

64. Today's 45 year olds demand childcare, out of school care, maternity allowance, baby bonuses and parental leave. Many live in two storey, five bedroom, three bathroom McMansions with two (environmentally irresponsible) black SUVs, and they have outsourced everything – including housework, washing, ironing, gardening, lawn care, pool care, child care, after school care etc. Many have neither the time nor inclination to care for their own children, let alone their grandchildren <u>or</u> their parents.

65. They have paid superannuation all of their working lives, into a fund of their choice, and they have worked under strict OHS conditions. Being potentially much healthier than today's 85 year old, they are far less likely to have chronic disabling conditions. They also expect to be self funded retirees and, as such, will be providing for their own aged care in a facility of their choosing.

66. Many have an expectation that they will inherit; and they have financial advisers and lawyers who are helping them to hoodwink older relatives out of assets by abusing family agreements and/or EPAs – and we have aged care providers getting in on the act as well.

67. Having little exposure to older people (who have been bundled off to 'gated communities') this younger mindset does not share their grandparents respect for older people, and too many have a dangerously callous attitude that older people are like locusts, taking valuable resources but giving nothing in return. Hitler would be proud of them.

68. As seniors we have experience of being young and foolish. Many of us can still recall the folly of being selfishly competitive, ignorant and inconsiderate. Young people have yet to learn from the experience of growing older and (hopefully) wiser. Many younger adults are consequently are actively and shamelessly bullying and discriminating against older people – both in and out of the workforce.

69. I regularly hear older people complaining that too many young people have muscled their way into roles as spokespeople for the aged, when they lack both the necessary knowledge, experience and understanding. We don't need or want generational change; we want attitudinal change – and legislative change that prohibits age discrimination in all facets of society.

70. You would have to have your head in the sand if you didn't know that many older people would choose to continue working, given the option, and many would be far more productive than less experienced younger workers. The Productivity Commission,

especially, would do well to strongly advocate for the removal of all age restrictions on workforce participation – including in the armed services or the judiciary. All positions should be merit based – and merit can include experience that younger people have not yet acquired.

71. In compiling your Draft Report, I presume the Productivity Commission would have considered recent research into the most common forms of disabling conditions in older Australians, and of how the demographics are expected to change in future decades.

72. I would have expected you to have considered the findings of the ABS survey in 2003[7] of *Disability, Ageing and Carers, Australia* and of the 2004[8] Australian Institute of Health & Welfare paper number 8 *Carers in Australia: Assisting Frail older people and people with a disability*. The latter of which states: "A comprehensive review of international literature on disability trends in 1998 showed evidence that disability rates among older people are decreasing in most industrialised countries." There is no logical reason why that should not be the case in Australia, and it is therefore entirely possible that demand for nursing home may have already peaked.

73. That ABS survey showed the most common forms of disabling conditions in care recipients over 65 were arthritis, stroke, back problems and sight loss.

74. All of us are nowadays advised to take preventative measures like fish oil and vitamin supplements, and being physically active, and eating Mediterranean diets. It seems, therefore, entirely plausible that – by 2050 - fewer 85 year olds will likely suffer arthritic conditions or back problems. Atherosclerotic disease, which leads to stroke and heart attack, is also much better managed, and far more preventative work goes into eyesight care – thanks to the likes of Fred Hollows.

75. Of course dementia is another condition that increasingly affects those over 85, but it is the one 'industry' which stridently argues that the incidence will increase – despite knowing much more now about the causes and mechanisms to reduce, delay or prevent neurodegenerative diseases, such as Alzheimer's and Parkinson's.

76. Very strong links have been identified between the incidence of Parkinson's and those employed in the agricultural industries who were exposed to herbicides and pesticides.[6] Again stringent OHS practices will likely contribute to a marked reduction, in the future, of such disabling conditions. However, much more controversial is the suggested correlation between dementia of the Alzheimer's type (DAT) and drug use – both over the counter and prescribed.

77. Today's 85 year old's practically grew up on 'a cup of tea a Bex and a good lie down'. Those who weren't taking Bex were encouraged to take Vincent's or 'harmless' Panadol and Aspirin for every little ache or pain. In the middle decades of the last century, umpteen women were routinely prescribed anti-depressant and anti-anxiety medications like Prozac, Stilnox and Xanax – after lobotomies were given a bad wrap. A strong correlation has since been indentified between benzodiazepines and cognitive impairment. There is also increasing concern about the possible adverse effects of cholesterol lowering drugs – the statins. Perhaps the drug companies, in particular, are cognisant that the incidence of dementia is yet to peak.

78. Experts claim that the four essentials for the care of people with neurodegenerative dementias is: early diagnosis; high quality care; treating the symptoms effectively, and; reducing the risk of developing dementia.[9]

79. You can't provide effective treatment until you have a differential diagnosis and, in our case, it took a three-year battle with belligerent doctors before I eventually wore them down and managed to get a differential diagnosis. In our case, the only way that any quality care was going to be provided was if I gave it. Sadly any chance of reducing the risk of developing dementia was lost in the delays in obtaining a diagnosis. Our governments don't see early intervention as a priority and, as a consequence, they are actively contributing to an increasing incidence of debilitating dementia.

80. It is also undeniable that the use of mind-altering prescription medications is much higher in nursing homes than in the general population – not least as a form of chemical restraint. The increased use of these drugs is also linked to an increased incidence of falls with traumatic brain injuries (TBIs) – which is the major environmental risk factor for development of dementia of the Alzheimer's type.[10]

81. Of course the drug companies reap enormous benefits from the use of PBS approved medications – and so the more people who are 'diagnosed' with Alzheimer's the more money goes into the pockets of the manufacturers (and the prescribers).

82. Of further concern is that fact that, despite "traumatic brain injury (being) the strongest environmental risk factor for the development of Alzheimer's"[11] it barely rates a mention in despatches. In fact, in Australia, not only is there resistance to efforts to collate data on TBIs in the elderly, those involved in TBI research, have been frustrated at their inability to obtain funding for preventative and rehabilitative measures for anybody over 65 (pers comm).[12]

83. Internationally it has been shown that TBI is both 'disease causative and disease accelerative' and that "the best predictor of decline (following TBI) was the amount of therapy received at 5 months post injury"[9]. Because people over 65 are, as a rule, getting no post injury treatment or therapy (beyond the initial critical incident), such a failure in preventative rehabilitative measures will almost certainly 'cause' and 'accelerate' an increase incidence of mental illness and dementias. Is that what the drug companies and the Alzheimer's Association is banking upon?

84. Imagine if dementias of the Alzheimer's type could be prevented - or its onset delayed by five or ten years. The savings would be in the billions, and the Productivity Commission would not be considering the factoring in of such an increased aged care 'burden'.

85. Have you ever pondered why the peak body purportedly representing those with over 100 forms of dementia, is called the Alzheimer's Association and not the Dementia Association? I have repeatedly asked the question, but have not received a satisfactory response. We don't call the cancer council the melanoma council or the leukaemia council. We don't call the Heart Foundation the Angina Foundation. Could it be that vested interest groups want society to make the incorrect assumption that Alzheimer's <u>is</u> dementia (when in fact Alzheimer's is a disease that – if you live long enough, or if you have an untreated TBI, or have a history of drug use – will likely result in your developing dementia)?

86. We all need to be very cautious about who benefits from such a misconception, and its impact on proposed reforms. If you are not aware of the cautionary comments of the UK's Michael Mandelstam, you may care to familiarise yourself with his latest report on the

destruction of the National Health System in the UK[13] by those who are 'out of touch with local realities'.

87. Michael highlights that "the chaotic change is being driven by concealed agendas – including privatisation … and abandonment of evidence based practice ... which particularly damages the most vulnerable – older people with chronic and complex needs."

88. If you are relying on advice from Alzheimer's Australia, you will have doubtless been presented with pessimistic scenarios. In Access Economics' recent report[14] *Caring Places: Planning for aged care and dementia 2010-2050* there is a forecast of a substantial increase in the number of dementia cases, and a consequent heightened demand for both residential aged care places, EACH and EACH-D packages and HACC packages (no doubt provided through Alzheimer's Australia). Of course that report was prepared with funding from Pfizer – the manufacturer of Aricept, the number one PBS subsidised drug for treatment of Alzheimer's.

89. There is no doubt that our aged care is in crisis but, in my opinion, it is because governments have outsourced aged care to the lowest bidder - which happens to be a cuckoo in disguise. It is time we slaughtered that sacred cow nonsense about bureaucrats being inefficient, whereas private enterprise or the not-for-profit sector is more efficient, more productive and more cost effective. Do we have to look any further than recent government funded roof insulation and school building rip-offs? If there is anything we should have learnt from the global financial crisis, it is that Government money (or private money) – without strict controls – is rorted; and the aged care industry is no different. They don't need less control, they need more control, and those who don't like it should be encouraged to get out of the industry – and if necessary buy them out.

90. As well as a buy back of nursing home facilities (and keeping vested interest groups like drug companies out of the decision making process) we need to get the middlemen and women out of Home and Community Care. You would be aware that many citizens won't donate to foreign aid because they know far too much is spent on duplication, inefficiency, administrative waste and corruption. Unfortunately, the same could be said of HACC funds in Australia. In some instances as little as 30% of the money allocated ends up being spent on direct services to the end user, with the bulk going to administration and duplication.

91. Far too many little empires appear to be springing up, with each governed by emperors who doesn't want to part with their money or the information they control – and I do not exclude Carers WA or Alzheimer's WA from that criticism. If it weren't for the Internet many of us would be denied access to vital information by self-servers.

92. The most equitable and cost effective option would be to pay HACC funding and EACH or EACH-D packages direct to the consumer, and cut out this behemothic myriad of waste. And please make the system consistent nationally. There is no justification for different states to have different rules.

93. It is often suggested that "the moral test of a civilised society is how it treats those who are in the dawn of life, the children; those who are in the twilight of life; the aged; and those who are in the shadows of life, the sick the needy and the handicapped." Frail aged are not just aged but also chronically disabled. They didn't choose to be that way, but they are almost certainly being discriminated against because of their disabilities.

94. Your proposed 'reforms' in your Draft Report unequivocally discriminate against disabled elderly people and, as such, are in direct contravention to the UN convention on the Rights of Persons with Disabilities[14], which states "discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person." That UN convention goes on to acknowledge: "the need to promote and protect the human rights of all persons with disabilities, includes those who require more intensive support." i.e. the frail aged. [my emphasis]

95. Older people who do have disabilities - and who do require more intensive support - must be afforded no less protection under the same UN Convention on the Rights of Persons with Disabilities as younger people.

96. The Productivity Commission appears to have plucked an arbitrary figure of 65 years of age, which unashamedly discriminates against people on the basis of chronological age. Under your proposal, a 65 year old would be expected to use the asset value of their home to pay for nursing home accommodation, but a 64 year old would not. We all know that some 65 year olds are fitter and much less disabled than some 45 year olds, and that some 65 year olds are more disabled than some 85 year olds. Age is of no relevance. To be anywhere near realistic, your criteria must be based on physiological age at least - and even then you would still be in violation of the aforementioned UN Convention.

97. If your proposed reforms were to be anything approaching 'equitable' you would at least include a grandfather clause that excluded all people who are currently 'in the system' i.e. limit the introduction of your proposed changes to younger people in today's workforce (say under 30), and therefore allow people to plan for their retirement in the knowledge that they will be expected to pay for their own care. Those of us nearing or past retirement age can't turn back the clock to our pre retirement years – and we can't get paid work even if we are fit and willing to do so.

98. Your proposal to remove the distinction between high and low care is also of great concern, because again it seems that the motivating force is to allow nursing home administrators access to the assets of all patients irrespective of the individuals care needs. Arguments in favour of removing the distinction between high and low care have included criticisms by some nursing home administrators that some Doctors, including ACAT Doctors, are certifying a person as needing high care when – following admission – the nursing home considers the patient only needs low care.

99. Obviously under existing arrangements it is to the advantage of the nursing homes to have the maximum number of patients assessed as needing low care. However, if Doctors are certifying low care patients as high care, presumably they are doing so in order to help patients who can ill afford the costs payable if they are admitted as low care (and will likely deteriorate to needing high care in the future). That being the case, your proposed removal of the distinction between high care and low care will surely further disadvantage patients who are presumably struggling – if that is the motivation for Doctor's making allegedly exaggerated claims.

100. However, I must offer some sympathy for the nursing home argument, not least because I have personally witnessed written opinions being given by Doctors (concerning the level of disability and care needs) when Doctors had not even seen the patient let alone made any attempt at an assessment. Those reports were provided following repeated pestering by interfering relatives who were seeking to gain control of perceived inheritances.

101. I have also personally witnessed deliberately erroneous reports submitted by senior medical practitioners in this state which have simply served to protect their fellow wrong-doing Doctors i.e. they have compounded such incompetence/corruption in order to protect professional colleagues who they believed "didn't deserve to get into trouble".

102. For those who remain deluded that all Doctors are above reproach, you would do well to make a comparison to that of paedophile priests – where the self-righteous church was more concerned with protecting its own 'brand' than preventing harm to the most vulnerable members of its flock.

103. At a seminar in Adelaide in September 2009[15], which was also attended by the now Aged Care Minister, Mark Butler, one of this country's most senior medical practitioners openly admitted that 'there is probably not a doctor in this country – including senior medical professionals - who is not "on the take" from drug companies'. (It was also pointed out that same symposium that Pfizer has been repeatedly fined for fraud and other potentially illegal activity – and that regulation doesn't stop bad behaviour unless it is transparent).

104. Instead of arguing over who is best placed to assess a persons care needs (ACAT teams or the nursing home), more stringent – and independent – and transparent procedures should be put in place to prevent anybody fudging assessments.

105. Which ties in with your suggestion that informal carers be 'assessed' for their capacity to be carers. Loving partners have always cared for each other, and your suggested assessment of their capacity to be an informal carer will likely place carers and care-recipients at further risk. Again, by way of comparison, we don't assess would-be parents for their suitably to look after children (maybe we would have less dysfunctional kids if we did).

106. Sadly, the outcome I envisage from your suggestion - in the absence of a transparent and equitable assessment process - is that vulnerable people won't seek help, but will instead lock themselves away in fear of 'big brother' interfering and splitting up loving couples who intend to stick to their vow of 'till death us do part'. Increasingly frail and vulnerable older people might even avoid getting medical treatment for fear of being dobbed in by 'on the take' doctors or administrators.

107. In fact, one of the most contentious (and abused) issues in elder care is the matter of capacity assessments; who should make them and how? If there is a need for an assessment of carer's capacity, then it must be a transparent and rigorous process – a process that adopts world's best practice. But before an assessment is made of the carer's capacity to care, an assessment needs to have been made of the care recipient's care needs, and before an assessment of care needs is made, an assessment should have been made of the care recipient's mental capacity to contribute to the process – especially given the increasing level of cognitive impairment and mental illness in older people.

108. Under the present system in this state we have Doctors who would deem a person as lacking capacity, seemingly for no other reason than to protect wrongdoers or to help others (including nursing homes) gain control of the care-recipient's legal and medical matters.

109. I would not have believed such corruption existed had I not had personal experience with a number of offending medical practitioners - one of whom I subsequently discovered was head of dementia related drug trials sponsored by Pfizer, the pharmaceutical company who manufactures the Alzheimer's drug, Aricept. Such a position of power and influence almost

certainly results in a conflict of interest, and yet the WA State Administration Tribunal – despite being aware of his conflicting roles - routinely calls upon the opinion of that doctor when making decisions about mental capacity (and SAT knows he refuses to follow transparent international best practice for capacity assessments).

110. My proposal for a transparent, fair and rigorous mental capacity assessment protocol[16] (copy attached) would best serve all concerned if it were adopted nationally. There is absolutely no justification for different processes on opposite sides of state borders, and my proposal would go a long way to protecting everyone involved from abuse or unfair accusation.

111. If there is a tsunami we should be concerned about, it is the current wave of elder abuse by greedy and dishonest family (and increasingly nursing home administrators) who enlist the help of unscrupulous lawyers and incompetent/unwitting/corruptible doctors and bureaucrats – and politicians who sit on their hands. However, instead of averting that tsunami, I fear the recommendations in your Draft Report will open the floodgate to more abuse.

112. Perhaps the saddest aspect of the hopelessness of the current crisis – with the lack of support and assistance to informal carer's - is the number of carer's who become so exasperated that they end up wishing their much loved care recipient would hurry up and die (and relieve the suffering of both of them) or they wish death upon themselves (and no longer have to contemplate a life of increasing poverty, social isolation and likely homelessness).

113. If there is a deterrent to despairing people taking such drastic action as mercy killing, it is that they could expect to spend the next ten or more years in jail and have any remaining assets seized under proceeds of crime legislation. Even if they were to use time spent in jail re-educating or retraining themselves, they would not be allowed to tell their stories (let alone profit from them).

114. For too many of in our predicament, murder/suicide may be seen the only 'humane' option. Is that the hidden agenda of the Productivity Commission's proposed Aged Care Reforms? To surreptitiously eradicate 'non-productive' older people, and to obliterate those foolish enough to put love ahead of greed? After you had 'come for' the disabled elderly, who did you intend to tackle next?

115. I recommend you carefully reconsider your proposed reforms, and keep Pastor Neuberger's famous poetic warning 'They came for me' at the forefront of your thinking. Care of the most vulnerable in a civil society is not an issue to be considered in the context of productivity, but in the context of humanity - and that means inclusivity.

116. Our elderly are not an economic burden; they are an integral part of society (not least because they remind us that there is more to life than money - and that there is more than one way to measure productivity).

117. Of course the overwhelming majority of doctors, nurses, care workers, administrators, informal carers and family are genuinely concerned - and doing the right thing – but those who are not, must be ejected and not protected. Whistleblowers should be similarly commended and not vilified. We all need to put a stop to the blame game and work toward a positive ageing blueprint. Older people are not, and do not want to be a burden on future

generations, and they should not be portrayed as such. We should all be able to look forward to living our twilight years fruitfully and respectfully.

118. The bottom line is, that your entire Draft Report is based on an assumption that there is a shortfall in (purportedly declining) available revenue relative to (purportedly increasing) demand. Of course there will be no need to find money for a shortfall if there is no shortfall.

119. Remove the inefficiency, the duplication, the corruption and rorting; get rid of the vested interest empire builders; focus on prevention and treatment of conditions likely to increase demand for nursing home care - such as TBIs and drug use (over-the-counter, prescribed and illicit) and acknowledge that Australian society as a whole is internationally obligated to provide for the aged and the disabled.

120. In addition to a plea for a more representative input of older people in the aged care debate, my parting shot would be for peak groups to desist with the current practice of appointing paid lobbyists, and 'celebrity' ambassadors, who appear to have little in the way of relevant qualification for their position – such ignorance only serves to detract from intelligent and informed debate.

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