

**Submission**

**To**

**The Australian Senate  
Community Affairs Committee**

**2006 Inquiry into the Funding and Operation of the CSTDA**

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## Some Facts that Forced the Inquiry to be Held

Among the several million marginalised and alienated Australian citizens today being forced to subsist at various levels of relative deprivation, poverty and hardship, are the unpaid family Carers of the several hundred thousand Australians with dependent disabilities.

For any Common-wealth, State or Territory ‘people’s representative’ or senior public servant ...sorry, Public *Manager*, with even a modicum of interest in the topic, the worsening plight of the 687,710 Australians under 65 years of age with dependent disability (the ‘potential population’ out of the 1,238,600 Australians with a severe or profound core limitation ‘expected to seek a service’) **and** their long-suffering family caregivers or “Carers” - is exposed in the appalling statistics and anecdotal evidence readily available for any who bother to look for or at either.

For these unfortunate and shamefully neglected citizens, their daily experience and life-chances - both current and future - can be characterised by that greatly (ab)used notion of being ‘in crisis’.

Little blame for their plight can be laid at the feet of these grossly exploited and abandoned Australians, commonly referred to as “The Disabled” and “Family Caregivers”, “Primary Carers” or simply “Carers” ... and by the well-rewarded senior bureaucrats and ‘service providers’ who ‘manage’ the disability sector and the broader society ... sorry, The Economy, of which it forms part, as “clients” and “consumers”.

For some ninety-three percent of the 687,710 Australians with dependent disability ‘expected to seek a service’, their year-round personal support and accommodation is provided by their immediate families. The great bulk of the financial burden incurred in providing this onerous task falls upon the family, with minimal support being provided by the state. This leaves only seven percent of Australians with dependent disabilities ‘expected to seek a service’ (some 48,140 persons) and the larger body of Australians with mild to moderate disabilities (who are) largely able to take care of themselves with minimal assistance from others (some 1,868,290 individuals) to be provided some form of assistance out of the billions of dollars said to be allocated to ‘disability services’, each and every year, across the nation, by senior Common-wealth, State and Territory administrators.

Yet whilst billions of dollars of public, taxpayer contributions continue to be allocated to the disability **industry**, year after year, the waiting lists for desperately needed publicly funded supported accommodation facilities, meaningful education or training programs, respite services and the like, continue to expand ... leaving more and more families in a state of genuine crisis and, in the case of the cohort of ageing parent-carers still providing care and accommodation for their ‘normalised’ and ‘independent’ adult children with dependent disabilities **STILL LIVING IN THEIR PARENTS HOME** in their 40s, 50s and 60s, UNMITIGATED ANGST OR FEAR by their family Carers **OVER WHAT WILL BECOME OF THEIR LOVED ONES WHEN THEY DIE!**

So how, then, can such a contradiction or paradox in a 'rich country' such as ours, with The Economy said to be 'going gangbusters', a record number of millionaire families and a new super-elite of some twenty or so *billionaire* families i.e. with **thousands** of millions of dollars of private surplus or capital wealth, and government budget surpluses now running into the billions of dollars on a regular basis, be explained?

### **Words, Words and More Words**

From the opening sentence to the last footnote, acknowledgement or official signature, the various multilateral and bilateral agreements between the Commonwealth bureaucracies and their State and Territory counterparts, *and* other official publications such as the Victorian State Disability Plan 2002-2012 are bloated with a plethora of fine-sounding managerial rhetoric, that subsequently fails, ignobly, to match up with everyday reality.

Drafted and later 'managed' (controlled) by often academically trained and credentialed 'model makers' holding well-rewarded senior positions in the various Federal, State and Territory governments' Treasury and Finance and Human Services bureaucracies, both the various pieces of disability legislation and the Commonwealth, States and Territories Disability Agreement (CSTDA) are replete with managerial mantras, ideological shibboleths and political-economic and social structures or relationships, the intended effects of which are to provide the casual or uninformed observer with the impression that all is well in the 'disability sector', and thereby obfuscate the reality of the true nature of the both the Australian disability *industry* AND the dominant, much broader politico-economic system currently in force - of which it forms part.

### **A Little History**

Ostensibly driven by the 1960s Scandinavian theory of 'normalisation', [today increasingly found wanting and rejected by growing numbers of people around the 'developed' (Western) world], the subsequent bureaucratically planned and 'strategically' managed process of 'de-institutionalisation' and alleged replacement with 'Community Care' across Australia, was quickly and cynically used by conservative forces in our society intent on 'Welfare Re-form' as a Trojan Horse ... to cost-shift the economic (tax) 'burden' of providing publicly-funded or 'government' assistance to Australians with dependent disabilities back onto the very small number of families who had been forced by circumstance to place their less than 65 year old family member in a publicly-funded 'institution of care' ... regardless of their economic or emotional capacity or ability to cope.

For the remaining ninety-three percent of families who steadfastly refused to place their disabled and dependent family member in a state-provided 'institution of care' – because of the shocking record of under-funding, neglect, abuse and mismanagement of the majority of such places - this 1970s 'strategic initiative' closed off forever any hope such families may have held for some degree of respite from their oppressively

onerous role of providing around-the-clock lifelong care and (expensive, special needs) accommodation for a seriously disabled daughter, son, spouse or other relative under 65 years of age.

The 're-formation' of the 1980s – which heralded the group home era – has had little impact upon the burgeoning waiting lists of people desperately seeking a supported accommodation service. At the end of two decades of transfer from congregate care to so-called 'community care', few families have achieved access. Victoria (at least) has faced the demon of cost blowout of the model and has ceased offering even this alternative to family care, leaving people with severe and profound disabilities at the mercy of piecemeal 're-form'.

Thus, from the 1970s onward, the families' disappointment was to quickly turn into fear and panic as a whole raft of other 're-forms' were unveiled, both in the disability and non-disability sectors of society, in order to save, protect or restore The Economy, which was said at that time to be 'ailing', 'depressed' and 'in crisis' ... not because of the endemic contradictions besetting it, but due to 'the unsustainability of the burgeoning Welfare State' ... Corporate Welfare excluded, of course!

To 'lift' The Economy or 'put life back into it', *WE* were going to have to 'tighten the belt' and 'share the pain' of 'de-regulation' and 're-structuring' in order to enable The Economy to 'get back on its feet' and make a 'full and speedy recovery'!

For unpaid and exhausted family Carers forced to survive on meagre 'allowances' and other fortnightly 'benefits' ... determined and doled out to them by senior 'executive' bureaucrats in receipt of 'performance-based' incomes of up to \$8,000 PER WEEK, the result of all this was a seemingly endless series of cutbacks and cessation of various minimalist 'services' and 'benefits' heavily relied upon by Carers to get through each day, each week and each year. Affordable respite - in particular holiday-length respite as enjoyed by every other 'worker' and 'executive' employee in the country, in the form of four weeks annual leave - became an ever-fading, diminishing dream ... a situation unaddressed to this day by our indifferent national and state 'leaders'.

Moreover, as for the several million other innocent and defenceless victims of the pernicious system extant ... injured 'workers', retired workers or 'pensioners', students from 'disadvantaged' or 'low income' families, un-employed and under-employed 'workers', physically and psychologically broken survivors of imperial war misadventures in far off places, innocent victims of motor vehicle and other 'accidents', the pernicious tobacco, alcohol and asbestos industries and so on, 'de-regulation' means an endless daily struggle to survive in the face of uncontrolled price increases in essential commodities such as foodstuffs, fuels for heating, cooling, cooking and transportation, insurances, housing, dental and other healthcare, healthcare aids and so on ... all fixed or determined by the notorious 'invisible hand' of 'The Market'!

As if such injustices were not enough, numerous vulnerable and defenceless individuals, families and groups – including people in receipt of meagre Disability Support ‘benefits’ are regularly ‘targeted’ by remote, unidentified and unreachable ‘executive’ bureaucrats for focused punitive treatment for ‘breaching’ often complex and unreasonable “Mutual Obligation” imperatives unilaterally imposed upon them. And although the contemporary Australian ruling class have yet to employ lethal force by the state to secure their politico-economic interests and quell dissent - as occurs in other ‘civilised’ Capitalist ‘democracies’ in North and South America and Western Europe - our prisons, streets and burgeoning ‘charity’ service providers ... mainly a handful of influential, well-connected, Judaeo-Christian religious organisations in regular receipt of a range of ‘government’ or taxpayer-funded largess, including tax-free status on their extensive property holdings for example, are widely known to contain a significant proportion of people with intellectual handicaps and mental illnesses.

### **A More Rational and Humane Paradigm Is Essential**

Now as Daly and Lewis (2000) correctly assert in their three dimensional conceptualisation of social care

- Care is labour
- Care is located within a normative framework of obligations and responsibility
- Care is an activity with financial and emotional costs which extend across public/private boundaries

(in Cass, Bettina Social Policy Research Centre, UNSW – ‘Estimating the Worth of Care: Policy Implications’ Social Policy in the City Seminar 18 May 2006 *Caring in the 21<sup>st</sup> Century: Costs, Opportunities and Custody*)

Elsewhere she points to an AMP.NATSEM Report on The Costs of Caring in Australia (2005) which “ ... compels researchers and policy-makers to understand comprehensively the ethics of care, the dynamics and social settings of care-giving and receiving ...”, concluding that “Choice over the life-course with respect to care provision and receipt requires that both policy paths be pursued.”

Cass’s five conclusions regarding (future) policy developments are compelling. They are therefore reproduced here, in full, as follows

- Beyond the analysis of informal care as an individualised, family-embedded set of activities and relationships, incurring privately-born costs (and benefits), public policies lie at the heart of the formal shaping and determination of caring relationship;
- Care must be understood within a policy framework: what are the impacts of federal and state social policy systems, family and carer income support, housing, employment conditions, family services, education, physical and mental health services on the circumstances and wellbeing of carers?

- Reciprocally, how are policies shaped by the expectation that care will be carried out within a normative framework of obligation and responsibility, which may be used to diminish the public responsibility to share the costs of these supportive and beneficial relationships?
- We should be developing conceptualisations and estimations of the “worth” of care, rather than focusing only on the costs of care. Caregiving and receiving is a relationship, providing worth and value to all participants in the private sphere and to society and government in the public sphere.
- Opportunity cost models of estimating the worth of care and its cost should not only be point-in-time, but look also to the potential impact of care-giving over the life-course.

Tragically, the narrowly educated, academically trained individuals currently dominating the most senior management positions in the public sector Treasury, Finance and Disability-related bureaucracies can only be viewed as completely devoid and ignorant of any notion of an ‘ethics of care’, or any similar social ethic, such as social justice. Obviously completely indifferent to the untold suffering being forced upon several million of their fellow Australians, because of the political dominance of ‘cost’ over ‘worth’ in their everyday considerations and ‘strategic’ policy initiatives and so on, these privileged young men and women in senior positions of public policy-makers and enforcers (‘Public Managers’) know only the ethic of self-interest ... individual career and financial advancement, their family socio-economic status and (limitless) ‘growth’ and, collectively, the economic and political interests of the managerial class as a whole, of which they are part.

The ‘blame game’ indulged in by these expert ‘players’ entrenched in the Commonwealth and Victorian government bureaucracies over CSTDA funding arrangements is diabolical, as is the fact that they have been allowed to get away with it for so long by the ‘people’s representatives’ to whom they are said to be accountable and the people they claim to serve. Still, the resultant public fiasco, together with several other critical social issues besetting our community, HAS awakened a significant portion of the Australian polity to the true nature of our class-divided, Corporate-bureaucratic ‘managed’ (controlled) Capitalist ‘democracy’!

### **What We Expect of You**

It is to be hoped that those conducting the 2006 Senate Community Affairs Committee Inquiry into the abject failure of the CSTDA to make any significant improvement to the everyday lives of the hundreds of thousands of Australian citizens with dependent disability *and* their often politically lauded but economically exploited family Caregivers, will publicly reveal, for all to see, *their* collective ‘ethic of care’, by acknowledging and moving, post haste, to redress the gross injustices forced upon some of the most vulnerable Australian citizens among us, and who are the focus of this public Inquiry and the many individual and group submissions you will receive.

To that end, I commend to the Committee the more detailed submissions and recommendations submitted by the self-funded National Carers Coalition and the self-funded Gippsland Carers Association Inc.