



SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

This is a 3 page SUBMISSION with a list of references and supporting documentary evidence from:

Edgar John & Rae Dainton,

We are aged parents (73) who have to care for our 26 year old deaf /down-syndrome son. We are concerned for his future when we can no longer provide for his 24hour/7day week (8760 hours per year) care needs. Ben is the youngest of our 5 adult children. Ben's elder brother aged 39 is deaf and is in receipt of the blind person's pension.

The "Disability Sector" is a national "industry" that serves the needs of disabled people. If all the funds at local, State and Federal levels of government were accumulated it could amount to billions of dollars. Yet from the "end consumers" point of view, the business of seeking help from this "industry" can only be described as entering a type of "jungle warfare." There is forest of commercially competing agencies which all need to make a profit out of providing a service. For those without the time resources and education it is very nearly a totally lost cause and they simply miss out. For those with the education and time it is literally a "negative ball-game" where the more time, effort and personal resources put in to dealing with this "industry" then proportionally less help is "offered".

The question we are all asking is: Why is there such a vast difference between the money allocated by State and Commonwealth Parliamentary budgets and that which is available at "ground zero" where it is needed?

Provider agencies are appointed through a government tendering process. They are commercially competitive. Most "Providers" are funded from duplicated "support systems" sourced from both State and Commonwealth Parliaments from many and often complicated pieces of legislation. Evidence also seems to suggest "providers" are outside the "mandate" of the Auditor Generals both State and Commonwealth levels of the executive government (refer annexure 5). There is evidence to suggest that the Australian Tax office is the only place where the "industry" funds can be traced. The obvious purpose of that would be for the return of disability funds back to the various State and Commonwealth treasuries through the tax system. From the political and accounting perspective, using the tax system of accounting for disability funds is a more expedient and a preferred method of "auditing". It obviously avoids Parliamentary scrutiny and capacity to audit the effectiveness of those budgets on the "target areas" funds were budgeted for in the first place.

For example, on Page 70 in the 2008/9 annual report of the W.A. Disability Services Commission shows that 257.6million out of a \$434 million budget is paid to "provider agents". Disabled people do not have any entitlement to assistance under the W.A Disability Act. There are nearly 21000 disabled people registered with the DSC. Grants for assistance are subject to some very difficult rules and conditions that are also subject to endless changes. The W.A. Auditor General has no "mandate" to audit this. Copy of his letter is included with this submission.

How often is this repeated throughout the nation?

And what chance does a family have of making long term stable plans for a disabled person in this legal quagmire? Especially for those with limited knowledge or experience to navigate such a "support system" whether for long or short term support.

With and "industry" or "support system" that is so fragmented and so difficult to "navigate" what chance has any family caring for a member that needs a lifetime support, got to plan for that persons future needs when the parents or sibling carer can no longer perform that 8760 hour per year caring role? With the experience of almost a lifetime in this jungle, what difference would a proposed National Disability "insurance" scheme make other than to increase the

complexity of the system and add an extra tax burden on the community when there is already a large portion of the national budget going into the full range of disabilities? All that could happen is that difficulties for the end consumer would increase along with increased costs for proportionally less help. That is the actual experience of the past.

The Commonwealth Respite Carelink Centres, (CRCC) refused to deal with Ben's own provider agency because they said their "guedelines" prohibited payments to an agency owned by a family member. The CRCC deal with several levels of agency systems each taking a proportion of the allocated budget. Each system has a barrier of rules of access. In our own case in May 2010 the CRCC made a short emergency grant of \$2575. The last retail agency handling this grant would have made a profit of between \$700 and \$900 after meeting costs. The profit represented about 20 hour of care Ben would have got if his own agency handled the grant.

This Senate committee may be interested in a new scheme commencing in W.A in July 2010 in which our son Ben owns his own provider agency. It is a 2 year pilot trial offered to him by the Western Australian Disability Services Commission (DSC). The business plan for this trial is attached. This new system has the potential to be developed into a scheme to help us and other families to develop into a system that can continue to fund Ben's long term care needs after we are unable to care for him.

It may be something this Senate Committee may wish to examine and report on. The development of this has the potential of reducing the costs of service delivery (brokerage) and increasing benefits including helping families provide for the long term care of their disabled family member.

It is acknowledged that the present Senate Standing committee enquiry is limited to this one problem caring families are confronted with on a daily basis, but there are many issues confronting families that, if not resolved soon may well impact on the rest of society. I particularly refer to some Constitutional and civil liberties that disabled people are being denied. I am asking this Senate Committee to consider these issues that are raised in the two documents and file of correspondence that accompany this submission.

Annexure 6 to this submission involves three letters between us and the W.A Disability Service Commission over the question of the end consumers right under the Act to receive an account of how a provider acquits a grant and is another example of the maize of barriers confronting disabled people and their carers.

Yours Sincerely,

John Dainton and Rae Dainton. 21 May, 2010

LIST OF LEGISLATIVE BARRIERS CONFRONTING DISABLED PEOPLE AND CARERS

1. Constitution of the Commonwealth of Australia Section 51(xxiii), (xxiiiA) and section 51(xxix).
2. International Covenant on the rights of Disabled People.
3. Commonwealth Social Security Act
4. Australian Taxation Act
5. Commonwealth Disability Services Act
6. Commonwealth Disability Discrimination Act.
7. Registration of Businesses (state and Commonwealth)
8. Human Rights and Equal Opportunity Act of the Commonwealth.
9. Western Australian Disability Services Act 1993

10. Western Australian Guardian and Administration Act 1990.
11. Western Australian State Administrative Tribunal Act 2004
12. Western Australian Workers Compensation & Injury Management Act 1981
13. Western Australian Employers Indemnity Policies (Premium Rates) Act 1990.
14. Western Australian Equal Opportunity Act 1984.
15. Western Australian Public Trustee Act 1941
16. Western Australian Business Name Act 1962.
17. Western Australian State Supply Commission Act 1991.
18. Western Australian Health Act 1911

LIST OF ENQUIRIES AND REPORTS ON THE NEEDS OF DISABLED PEOPLE

1. **The Senate standing committee on Community Affairs Report dated February 2007.** Finding and operation of the Commonwealth State/Territory Disability Agreement.
2. **House of Representatives Standing Committee on Family, Community, Housing and Youth.** Report dated February 2009 titled "Who Cares...?"
- * 3. **National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council, Report published by the Commonwealth of Australia in 2009. Titled "SHUT OUT People with Disabilities and their Families in Australia."**
4. Speech to the National Press Club on 1st April, 2009, by Hon. Bill Shorten, M.P. Member for Maribyrnong. Speech title was "Right to an Ordinary Life"
5. Australian Institute of Family Studies Research Report Number 16 by Ben Edwards Daryl J Higgins, Mathew Gray, Norbert Zmijewski, Marcia Kingston.
6. Report of the review of the W.A. Disability Services Act 1993 presented to the Western Australian Parliament in May 2009, By the Hon Minister for Disability Services Mr. Simon O'Brien, M.L.C.

End of page 3 of this submission.