

CSTDA SENATE INQUIRY (SEPT 2006) SUBMISSION

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Thank you for your acceptance of my late submission. I would like the opportunity to address the inquiry at an appropriate time.

"I met yesterday with a social worker desperate to find a supported accommodation position for a 40 year old intellectually disabled man. He has been on a priority waiting list for 8 years. His mother now has terminal cancer. The social worker has no answer.!"

This is the cruel reality of a national disability approach that has failed."

CSTDA NEEDS MAJOR OVERHAUL

The current inquiry into the CSTDA is much needed and very important to the 200,000 Australian's with a disability, their families and carers who depend on this program for essential life services.

The current CSTDA program has not worked for a number of reasons and needs to be radically updated or replaced

1. It is based on Disability framework's, established in the 1990's with a focus on avoiding the errors of the past (e.g. archaic institutionalized living) but lacking the forward vision enabling people with a disability to make the same life choices as the broader community.
2. The disability framework on which CSTDA is based, lacks balance and reflects more the wishes or intention of vocal disability sectors to whom total independence is an ultimate goal and has failed to balance the wishes of the broader disability sectors need for balance and choices ,leaving wide divisions in the sector as people with a disability ,their families and carers debate disability philosophy versus priority of need and adequate provision of services.
3. Questionable political, correctness and government focus on questionable priorities has distorted the disability debate to the detriment of service provision to a broad range of disability recipients.
4. There is a lack of balanced, independent , key advisory groups and governments ,both state and federal, have been able to avoid scrutiny and accountability due to a culture of fear that pervades the disability sector regarding disability service funding and it's possible withdrawal.
5. The Disability framework does not broadly reflect the choices and wide ranging wishes of people with multiple forms of a disability, their families and carers
6. The undertakings financially within the current and past CSTDA agreement have been totally inadequate to match disability sector need with the resources provided and address unmet need and increasing demand.
7. The previous CSTDA agreement's have provided a questionable safety net to both state and federal government whereby they can rationalize their failure to deliver adequate support to the disability sector on the basis that they are meeting the agreement.
8. The CSTDA agreement's have resulted in essential services like supported accommodation being the sole responsibility of the states who are unable and unwilling to fund the massive costs needed to provide this ongoing service to recipients while excluding federal government from supporting this key area. The allocation of responsibilities needs to be changed.
9. The CSTDA agreement has fostered a system whereby disability support is provided by an extraordinary number of small, ineffective and inefficient Government and Non Government Organizations (NGO's) whose levels of accountability are not closely monitored causing extraordinary waste of valuable disability dollars on infrastructure, salaries and on costs to the detriment of provision of support services.
10. The CSTDA agreement's have failed to establish minimum benchmarks of adequate provision of services by both state and federal governments based on need .
11. The CSTDA agreements have failed to incent (or penalize) states for meeting the agreement.

12. The CSTDA agreement has failed miserably with disability support and services being unavailable to a wide range of recipients, highlighted by extraordinary waiting lists for key services on a National basis.
13. The CSTDA agreement has failed to address or support the care provided to families and carers who are forced to shoulder support programmes not provided by the state and federal governments despite their essential need.
14. The overwhelming question of people with a disability, their families and carers of "what happens when I die?" remains unanswered.
15. The CSTDA has failed to address that the situation regarding disability support and services deteriorating and the current models are unsustainable.
16. Disability support needs to be a COAG agenda item as a matter of urgency
- 17.

Clearly the widespread disability community angst that has been evidenced by an increasing number of state based sector campaigns highlighting the inadequacy of disability support reflects many of these concerns.

SUPPORTING INFORMATION and EXAMPLES

ITEM 1, Disability framework out of date

Both the NSW and SA state governments have held detailed public inquiries into disability services in the last 18 months. After extensive consultation with all stakeholders regarding supported accommodation in NSW and day options in SA both states found widespread demand for choice including congregate services which are contrary to the disability framework. This is hardly surprising given the rapidly expanding wider community desire for options and choices including high density, inner city living, village style or community living, or in home family supported living (for aged care or children) that the broader community has demanded and accessed in recent years. Variations in living styles is one of the fastest growing demographic community trends in the last decade. Why the disability framework would push people only into independent or very small group, community living and social interaction situations (often with significant isolation effect and inadequate support and transport) is outdated and should be changed. The ease of access, social interaction, personal security, personal support mechanisms desired in the broader community should also be available to people with a disability based on their needs and choices. I was horrified to read a submission to this CSTDA inquiry from Uniting Care S.A. disparaging the rights of people to choose their model of service. The broad community consultation and outcomes of both NSW and SA totally reflects today's client driven issues, of choice and appropriate resolutions. While clearly fully independent living (and self funded packages) should be available by choice to those who want it likewise a full range of other choices should be available based on personal needs.

ITEM 2 It is disturbing that much of the disability policy appears driven by people with physical disability and the capability to voice loudly their needs and concerns. Given that by far and away the greater portion of people supported by CSTDA are intellectually disabled (41%) and by the very nature of their disability unable to speak on their own behalf (and may have very different needs) the question of policy balance (refer Item 1) must be addressed. The Federal governments failure to establish a joint carers/people with a disability advisory committee (a process started 18 months ago) is concerning. It is common place under the guise of "people with a disability speaking for themselves" for people with physical disabilities to chair or control the majority of advisory committees. It is concerning to families and carers of people with intellectual disabilities that the Australian Federation of Disability Organizations will only accept on its board people with a disability and purposefully excludes carers and family members. Such unbalanced advisory processes potentially impacts on the priorities, broad range of needs and solutions that are required to fully address broad disability need.

An example highlighted to me recently was when a local mayor complained bitterly that councils in SA would need to spend \$1.3 million dollars to make bus shelters wheelchair accessible, a cause rightfully championed by physical disability advocacy groups. At the same time hundreds of people with intellectual disability are totally unable in SA to access any form of transport support (buses, cabs or trains) and remain isolated or totally dependant on their carers. It is simple to understand the angst and annoyance of these people who feel more ultraistic issues are being addressed whilst basic services remain not funded

ITEM 3 As above, item 2

ITEM 4 On March 31st 2006 the Adelaide Advertiser ran an article quoting SACOSS where Disability advisory and support groups were being forced to sign funding agreements including clauses that they were unable to comment publicly on their area of expertise and needs. Such an approach is like something from communist china? The silencing or shutting down of the debate on social issues should be illegal and governments, ministers or public servants engaging in such practice should be exposed and penalized under the CSTDA.

Prior to the last state election in SA it was alleged to me by an employee of an advocacy group in SA, that she was pressured as an employee with loss of salary/employment, forced to sign a confidentiality agreement and offered counseling by her employer to dissuade her from being politically active as her agency did not want to jeopardize their funding. This approach is reflective of the culture of fear which stifles critical debate in disability support services.

ITEM 5 as above ITEM 1 and 2

ITEM 6 An IDSC board paper widely reported in the Adelaide press in Oct 2005 shows demand for IDSC services has risen 16% per annum for the last 7 years. Disability funding has risen at a rate of 5.2% pa (nett of inflation) in SA during this same period. The lack of services and waiting lists have been described by SA Disability Minister Jay Weatherill as "extraordinary". There is effectively no planned movement in waiting lists in SA (other than lengthening). Families are in crisis, services are unavailable and the system can clearly not be sustainable unless financial support progressively addresses unmet need and future demand. The SA government should be complimented for currently reviewing this area

The failure of CSTDA to deliver appropriate financial support has been significant and a major contributor to this crisis

ITEM 7 A review of the CSTDA funding history shows state and federal governments have adopted a minimum requirement approach to CSTDA funding with no correlation to need and unmet need.

ITEM 8 The AIHW report released on AUG 31st 2006 shows that just 4.8% of the future national need for supported accommodation is being met by the states. The 33,787 people currently being accommodated by the states are being done so at a cost of \$1.7 billion dollars per annum. Whilst the calculation of this future need is quite complicated it is painfully obvious that the future cost per annum is potentially enormous (\$35.4 billion), clearly beyond the states capability.

In SA in the last 10 years supported accommodation has basically been supplied on an absolute crisis basis of family collapse, carer death or abandonment. Waiting list positions are not available.

The Australian productivity figures released in Jan 2006 show that while disability supported accommodation vacancies in SA are terrible, most other states are worse off.

Whilst it is imperative other accommodation options need to be explored under the disability framework clearly accommodation either needs to become a joint federal/state initiative or the federal government needs to take control. The size of the problem is beyond the resources of the states.

ITEM 9 The financial wastage and duplication in the Disability support area is appalling. Small, ineffective organizations, including NGOs, dissipate millions of dollars in badly needed service funds. There are 142 NGO organizations in SA serving 20,000 clients. One organization allegedly has 1 client?? The duplication of boards, CEO's, offices, cars, photocopiers, admin staff, staff duplication and waste of resources must be addressed.

Some organizations do an outstanding job but some are more habitual conference goers, questionable empire builders and should be amalgamated or closed. The SA government should be complimented on its recent amalgamation of 3 major SA government agencies. We trust the change delivers the efficiencies and improved services that are expected from the rationalization.

Two recent irritating SA examples of wastage include Disability Action being defunded and SA losing \$500,000 in badly needed disability support funds and another NGO allegedly having two staff attend an overseas conference, and then using the free air tickets as the basis of a holiday at the conference destination.

Disability services should be restructured so the dollars deliver services to more clients

ITEM 10 The CSTDA must establish population based benchmark levels based on Disability need. The federal government has implemented a similar plan with the aged care system which could be used as a framework. The establishment of clear benchmarks for disability support based on numbers of people needing support should be a key component of the CSTDA. These benchmarks should cover all key areas of disability support including accommodation, transport, support services and respite. These benchmarks should establish basic standards and future growth coverage and all states should be legislated to comply and incented to do so.

ITEM 11 States should be motivated and incented to exceed CSTDA targets by the CSTDA agreement

ITEM 12 covered

ITEM 13 The \$97.00 per fortnight paid to my wife as primary carer equates to a payment rate of 28 cents per hour for the 24 hour per day / 7 day per week care our daughter requires. There is no doubt that as the general population ages the number of people with disabilities who will require care will escalate rapidly. Baby boomers will not provide the lifetime care that the government is used to receiving. Whilst we like all love our daughter dearly her size, her behaviour and her physical demands will not be able to be covered by our family and 28 cents per hour provides little outside support.

Whilst the federal government has made a priority and channeled tens of billions of dollars into security, defense, detainees, aboriginal support, tax relief and health services they have done so to the detriment of the disabled, their families and carers and the system is not sustainable. Rebuilding disability services needs to be a priority.

ITEM 14 With a AIHW report based estimated \$34.5 billion potential need for supported accommodation costs unmet, the biggest question of what happens to people with a disability when their supporters, families or carers die or are unable or are unwilling to provide further care remains unaddressed. At a time when volunteer numbers are diminishing the lack of future planning for disability support is damning on the current Federal government. It is notable that the federal government is establishing a "Future Fund" to cover the generous (up to 15%) superannuation entitlements of federal public servants (contributing initially \$40 billion dollars) but there is no planning in place to address the future needs of people with serious and multiple disabilities.

ITEM 15 Covered

ITEM 16 I have written to the Hon Mike Rann, Premier of SA asking him to table this submission at the next COAG meeting. The SA government has very much understood and taken a number of steps towards addressing the crisis in disability support that has built up in SA over the last decade. Clearly he and his government will be unable without a quantum change in the CSTDA funding arrangements and significantly increased federal government support be able to address these issues.

The 200,000 CSTDA recipients are amongst Australia's most vulnerable citizens. They need help!