

Nell Brown unpaid carer of over 20 years

**Submission to the Senate  
Community Affairs Reference Committee  
Inquiry into  
The Funding and Operation of the  
CSTDA**

**IT IS TIME TO  
SEE, SPEAK, HEAR  
BUT MOSTLY IT IS TIME  
TO DO SOMETHING**

**About the systemic failures of the  
Commonwealth State & Territory  
Disability Agreement**

**Submitted by Nell Brown  
Carer of my daughter Tess who has lifelong dependant disabilities**

It is hard to even begin to write this submission.

Where does one start when everywhere you look are gaping holes.

The CSTDA can be likened to trying to fill a bath when you only have a 1/4 of a plug.

It would have been more appropriate to ask the question, what is right with the CSTDA?

The spirit of the agreement is terrific, the ideal of putting services in place that allow some equity in the lives of people with disabilities is laudable, but *words are cheap and services for the disabled are not.*

The CSTDA fails more than 90% of the people it is supposed to assist.

It promises nothing, no supports are mandated, which is what most people in need get – no services, unless they have a carer who is willing to devote a good part of their life to battle with the dept responsible for assistance.

*We live in fear of not getting services, yet if lucky to do so, live in fear of losing them at the stroke of a pen, at the whim of the minister of the day.*

This submission is about developmental disability simply because physical disabilities in isolation are far more easily overcome to live rewarding and challenging lives than intellectual disabilities.

For the physically disabled/challenged with fully functioning intellect, not only are their rights to self-determination self-evident but other similarly obvious concessions are made with an endless lists of aids.

**For the developmentally disabled, particularly in the moderate to severe range, few protections or concessions are made for their compromised intellectual function.**

For so many people with an intellectually disability, their ability to function in isolation is seriously compromised, which means that to live an equitable life they need the assistance of a second person in every day activities.

This is where the failure of the CSTDA begins its massive downward spiral.

The CSTDA is so grossly under-funded it fails to put these supports in place and by default it coerces, indeed forces family members into giving up their social lives, their working lives, often their family life to be that 2<sup>nd</sup> person, and not just in the early years.

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It is the normally socially accepted parameter to care for your children, to nurture their development so eventually they can go forth into their own futures, futures filled with their own choices, their own hopes and dreams.

But this is not true of families whose beloved children/adults have severe/profound disabilities, because the disability system is one of systemic failure, our children who have grown into adults are not offered these choices, they need the support of a 2<sup>nd</sup> person and fewer than 3 in every 100 (my state of NSW) people are given the funding to achieve an acceptable level of independence away from the childhood home.

Fewer than 3 in every 100 (NSW) people are funded for accommodation supports.  
Fewer than 8 in every 100 (NSW) people are funded to access community support.  
Fewer than 3 in every 100 (NSW) people access community inclusion activities.  
Fewer than 6 in every 100 (NSW) people access respite care services to give their unpaid carers a break.

*FAR TOO MANY FAMILIES LIVE IN TERROR OF WHAT WILL HAPPEN IF THEY DO NOT CONTINUE THE FREE CARE AND SUPPORT ROLE*

*It stands to reason that AUSTRALIA HAS TOO GREAT A PROPORTION OF IT'S CARING POPULATION TERRORISED BY THE LACK OF WILL OF GOVERNMENTS LED BY GOVERNMENT APATHY TO THE PERSON WITH DISABILITIES, TO ASSIST THEM ATTAIN ANY LEVEL OF INDEPENDANCE*

*\*No one who is interested enough to be reading this submission will be unaware of this already.*

*We can always have more of these inquiries, but if the prescribed recommendations of these inquiries sit gathering dust in the drawers of the Minister for Community Services and the incumbent government as other reports have done then the whole exercise will be another a waste of time.*

**THE QUESTION IS, ARE WE GOING TO DO SOMETHING BEYOND SLAPPING YET ANOTHER BANDAID ON CRISIS, IN AN EFFORT TO DERFER EVEN MORE CRISIS, IN AN TO ATTEMPT TO HIDE THE SYSTEMIC FAILURES OF THE Commonwealth State & Territory Disability Agreement?**

**OR**

**ARE WE REALLY GOING TO DO SOMETHING MEANINGFUL ABOUT IT THAT WILL BRING ABOUT CHANGE AND HOPE FOR THE FUTURE OF THOSE OFFERED NO/LITTLE HOPE?**

***CHANGE WILL NOT HAPPEN UNLESS THE FEDERAL GOVERNMENT TAKES A STAND.***

***THE FEDERAL GOVERNMENT AT WORST, MUST BECOME A MORE THAN EQUAL PARTNER IN FINANCING DISABILITY SERVICES.***

***AT BEST THE FEDERAL GOVERNMENT SHOULD DECIDE TO TAKE CONTROL OF THE CARE AND RESPONSIBILITY FOR AUSTRALIA'S MOST VULNERABLE PEOPLE.***

***WE MUST PROTECT THOSE WHO'S CAPACITY TO LIVE REWARDING LIVES IS DEPENDANT ON THE SUPPORT AND CARE OF A SECOND PERSON.***

***IT IS AN ISSUE OF CITIZENSHIP.***

We, as a nation, feel defined by our generosity in times of trouble across the world, we are willing to fight for the rights of everyone and everything from refugees, to political prisoners, the sovereignty of other nations, for whales, for native parrots, right down the scale to family pets and yet;

***We are willing to leave Australian citizens living with lifelong disabilities where they are, at the back of the pack.***

**In limbo.**

**WHY?**

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So many families are living in desperation, and fear, massively depressed as so many are forced into unending poverty and depression due to government apathy and neglect in adequately funding necessary services.

Will our politicians continue announcing that we are throwing a few more crumbs their way as if they were inviting a starving man home for a Sunday roast, only to have the man discover he is really being offered the scraps of a nearly finished meal?

Disability funding for resources for a more equitable life *are not handouts*.

*Funding disability services in the 21<sup>st</sup> century should be viewed as a hand up, just as education, medical care and potable water are not handouts, but an expectation of a reasonable quality of life.*

***DISABILITY SERVICES IN OUR WEALTHY NATION SHOULD BE A RIGHT.***

A reasonable quality of life is a fundamental human right, one that is being knowingly violated in our country by all levels of government in respect to the CSTDA.

*In fact many families view the CSTDA as a useless agreement which allows, even encourages the States, Territories and the Federal Government to sit around like petulant children pointing fingers and playing the blame game, scoring cheap political points off each other.*

Whilst politicians continue to play this blame game, unpaid carers of profoundly and severely disabled people are political prisoners.

Prisoners of the blame game being played out in our parliaments, both state and federal.

It is not even mildly amusing that when in opposition, the opposition members speak out for the disabled and their carers, cannot wait to use us to score points off the ignorant and smug incumbered politicians who believe they can ignore the human rights abuses, but when they become the elected government, they turn around and perpetuate the abuse.

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This is just what Australia's political parties have been doing for years, since they realised that points can be scored, that words are cheap until after the next election and unpaid carers are too immobilised by fear, too tired and too depressed to really take them on.

***Isn't it time we grew up as a nation, indeed we could skip the whole adolescence thing and throw ourselves into some real adult behaviour and work together, do the decent thing and try to FIX THE APPALLING BLOODY MESS!***

Family carers and people with disabilities are all too often prisoners of their homes, denied access to the Australian way of life that for others is accepted as a right. Unpaid carers are far too often denied the opportunity for an honest pay for an honest days work, because the loved one they care for is not offered enough care under the CSTDA to allow the unpaid carer the opportunity to work.

No support in place equals lack of community equity, not only for the disabled but also for the person who is expected to carry the entire burden of care, unsupported and unpaid.

In a wealthy society such as ours it is indeed an injustice to demand that mutual obligation is a one-way street.

As a society we do not expect young mothers to be chained to their homes, we put in place accessible childcare, and caring full time for a child is at worst a 5-year full-time, 24/7 job.

For the child with severe/profound developmental disabilities the caring role continues onward through adolescence and continues into old age. The concessions governments make to this are virtually none.

Out of sight, out of mind is Australia's sorry response to the plight of the disabled

***Appallingly, Disability funding for those under 65 is only funded at around half that of Aged Care.***

***Given that 89% of the disability cohort is under the age of 65, we have a discriminatory service system that agrees to assist and support people using a cynical, unfair and discriminatory age divide.***

***These funding levels have nothing to do with the degree of either disability or incapacity, they are purely based on a stupid notion of age, or aged related disability.***

***Disability funded services for the aged, are uniform throughout our nation.***

***Disability funded services for the under 65's are ad hoc, confusing, have neither benchmarking, nor consistency throughout our nation.***

***Every state and territory operates in isolation, the systems of support delivery differ, and costs of bureaucracy are repeated 8 times instead of managed by one department.***

**The costs administration of the funding for CSTDA services in NSW alone, were 111million out of a budget of 992 million, the national average is 9%**

Sources: SCRCSSP 2005: Table 13A.37; and data provided to AIHW

***\*Why are parents of adults with severe/profound developmental disabilities, offered no choice but to give up their entire lives to the caring role, when as a society we do not expect the sons and daughters of aging parents to give even a moment of their financial, family and recreational life for the final years of an aging parents life?***

***\*\* We get back to choice for some, not for others, based on an artificial and discriminatory age divide, with funding levels so inadequate for Australians who have their entire lives before them.***

***\*\*\* Some all-of-life-carers are so much older than the sons or daughters of aging parents, yet we seem to continue to coerce these parents to live a life paralysed with fear of an unknown future for their sons and daughters, or they simply collapse with age related disabilities themselves before we grudgingly offer accommodation services.***

**\*\*\*\*Some aging carers access services for their age related disabilities, yet are expected to continue the care roll – because governments absolve themselves of responsibility simply because they can...**

## A QUICK QUIZ

**The Federal government funds aged care and the states fund under 65 disability services. The amount of people needing services by the states is practically at 9x the amount of people needing aged care services funded by the federal government.**

**1. Do the States have far more money than the Feds?**

YES

NO

**The Federal government use figures of funding for disability services, because they pay pensions and they pay for employment services.**

**2. Does the federal government use the pension figures, the Family Tax Benefit figures or the employment services figures when they are discussing funding for pre-schools**

YES

NO

**3. Does the Federal government use similar figures of sickness benefits, pharmaceutical funding etc when they talk about funding medical services?**

YES

NO

**4. Australian States collect 16 per cent of total tax revenue, so it stands to reason that they are expected, and do, deliver 16 per cent of services**

YES

NO

**\* Surprisingly the states are responsible for 40 per cent of total government expenditure, including 50% of all government services.**

\* From Benchmarking Australia's Intergovernmental Fiscal Arrangements by Dr Neil Warren

**\* If you answered NO to all the above questions are you are correct.**



***Given the Federal funding and taxation input versus the responsibility of the states in service delivery, these failures are hardly very surprising, are they?***

There is a myriad of disability advocates whose function is to speak on behalf of the disabled.

How do you speak on behalf of people with severe/profound developmental disabilities, when the person who spends the most time with them, who understands their needs, desires and wants, who knows their strengths and weaknesses are not consulted?

All ministers who control the funding levels, who make decisions on disability services should look to unpaid carers, whose loved one falls under the CSTDA net and include them in discussions on care needs and supports, after all they are currently responsible for over 90% of disability services, albeit unpaid, unsupported and unrecognised. As it presently stands, usually the only consultations are with paid workers within the disability industry.

Disability advocacy is led by the ideology, indeed the right, that people with disabilities should be given the opportunities for enjoyment of life, that everybody else accepts as a given.

These opportunities can only come about with community inclusion, community support.

This hopefully is just what happens for most people with a disability, the community sees past the limitations and our acceptance of any individual is based on the desired qualities of the person.

What then of those who cannot intellectualise? Those who often stumble on the simplest of decisions? Who cannot be left alone because they do not have the capacity to understand danger, to understand basic self-preservation?

What if they do not have the skills to communicate their needs?

What about those who have behavioural abnormalities, whose social interaction is limited, those who self harm, or indeed harm others?

How do these people become included and live rewarding lives within the community, how does society accept these people?

Human relationships are forged using compatible bonds. If the reader looks at their own friendships, their social interactions, I am sure they are based on SIMILAR, and the most similar of these bonds is intellectual ability and social interaction.

*How then, can we then expect the person, who is born with the greatest level of differences not to become marginalised nor ostracised, but to be 'socially valid', if we do not put in place the resources to assist them to be the best that they can be?*

*If a person begins to present with challenging behaviours, we put them on a list. One, two or three years later, by which time the behaviours have gone from mildly challenging to acute, then, they will perhaps, if lucky, be given minimal support but by then the adverse behaviour has been set.*

*If the caregiver fails to harass the dept constantly, their name just magically vanishes from the list and the process must start all over again.*

*There are waiting lists for every service, more often than not years long. More often than not if lucky enough to even receive services, they are too little, too late, to do more than dance around the edges of the underlying need.*

*We have failed to understand immediacy is our greatest hope.*

So many children with developmental disabilities also have difficulty with speech, with mobility issues, with low muscle tone, with coordination.  
The services offered are minimal; *these children will grow into an adult who cannot communicate adequately, they are physically compromised, have challenging behaviours which manifest from frustration at the everyday difficulties and challenges they face.*

*ALL these factors will make them hugely more expensive to maintain across a lifetime.*

*All these factors marginalise and stigmatise and isolate.  
These are the failures of inadequate funding levels of the Commonwealth State & Territory Disability Agreement.*

The reality is the States and Territories either  
***DO NOT WANT TO SPEND THE MONEY, OR THEY CANNOT AFFORD TO DO SO.***  
***LONG TERM THEY CANNOT AFFORD NOT TO***

The alternate reality is this; ***WE CANNOT AFFORD NOT TO.***

***AUSTRALIA CANNOT AFFORD NOT TO***

***Every dollar spent now is possibly hundreds of thousand saved in the future***  
***All this is cost shifting off, to future crisis management to a future government***

***The ridiculous reality is that there are only two parties who control state and federal government so this concept is a crock, sooner or later they will have the problem dumped once more into their laps.***

***By not speaking out, by not looking for answers, by not listening, the inescapable reality is you are all damaging your own future viability as an elected, controlling and viable government.***

***Sadly the hardest thing must come first.  
First there must be political will for change.***

### **THE SILENCING OF THE UNPAID CARER**

The National Advocacy Review, which recommends carer advocacy that mirrors disability advocacy, as well as other reports on this subject, have been gathering dust in Canberra.

We have to suspect it is by design.

Another National Advocacy review has just been completed; perhaps this inquiry can get hold of a copy and include its recommendations to this inquiry.

We have carer's information resources such as Carers Australia, the state bodies such as Carers NSW, VIC, ACT, NT, SA, and QLD. WA and TAS but their advocacy is passive, it does not mirror advocacy for the disabled, and its main function is for carers of those who meet the criteria for aged care services.

For example, from Carers NSW website:

Carers NSW works continually to build awareness of carers' needs and represent their interests through our research, policy and advocacy activities.

#### **Carer Support Programs**

Carers NSW works with a wide range of carer groups including Indigenous carers, multicultural carers, young carers, carers of people with a mental disorder, carers of people in residential aged care and carers in a palliative setting.

Our Current Programs:

Aboriginal and Torres Strait Islander (ATSI) program

Carers Linked in Caring (CLIC)

This program is concluded and the evaluation report is pending.

Carers Mental Health Project

Multicultural Carer Profile Project

Palliative Care Project

Young Carer Project

**No mention of unpaid carers who are coerced into caring for 30, 40, 50, 60 and more years with inadequate supports and assistance.**

**Given that there are far more carers whose lack of services fall under the CSTDA than any other carer group, this is a disgrace and must become a priority.**

**Have the state and federally funded carers peaks called for carers to make submissions to this inquiry?**

**Is information on how to make a submission to this inquiry posted on their websites?  
NO, SO WHY NOT?**

Governments cannot expect carers to carry most of the disability load (unpaid caregivers are currently responsible for over 90% of all services) while giving them no way of actively engaging in their own futures, and the future of their beloved family member.

Carers of those eligible for CSTDA services must be given a voice.

## **OCCUPATIONAL WORK AND SAFETY**

Would appear to have neither state nor national standards.

We have disability support workers refusing to lift 40-kilo children to assist with personal care and hygiene (even with hoists in place).

Within the same state, possibly in the house next door, they can and do, lifting far heavier weights, depending on who funds them.

We have in home respite care workers refusing to take the cared for person out of the house to give families a break (too dangerous). The family must leave the premise if they want respite, so instead of exercise and recreation the person with the disability stays in watching TV or some other passive activity.

How does the carer afford to go anywhere? If the carer stays at home, the cared for person turns instinctively to the unpaid care, so what is the point of paying for the care in the first place? Few families can afford the luxury of care, or indeed the luxury of a holiday.

The family must leave the premises to achieve respite.

Within the same state they can and do, (possibly from the house next door) take the dependant person for walks, outings, shopping, even exercise classes.

It all depends on which dept funds a percentage of the paid carer. Indeed from which pool of money that funding actually comes, and *what the occupational work and safety policy of that particular agency is.*

Ridiculous? Of course, so much in disability services is unworkable and ridiculous.

## **Mental Health Care and services for the developmentally disabled**

**WHAT ARE THEY?**

**WHERE ARE THEY?**

**Disability hands you over, mental health hands you back!**

## **Health Care for the Developmentally Disabled.**

**A minefield for families, because there is very little understanding by governments that any old doctor just won't do.**

I have read many reports to the Dept Health on Disability Health Care and Disability Mental Health.

***It is too easy to ignore the fact that Health Care outcomes are as bad for the intellectually disabled as they are for our indigenous population.*** (Bittles & others 2002, Beange & others 2002, Scott & others 1998 Stewart & others 1994, Community Services

Doctors not trained in specialised disability care are faced with an onerous task. Many try extremely hard to assist but find they are limited because of lack of ability to interpret and understand due to limited language skills of the client.  
Some doctors are just plain disinterested.

People with severe/profound disabilities need differing areas of government to act together to provide services, the complexity of problems means health and disability cannot operate successfully as entirely separate entities; they must be intertwined for best outcomes.

We need a specialised intellectual disability health resource hospital in every city with a large population. A multi-disciplinary team of doctors and clinicians who specialises in intellectual disability, speech pathologists, neurologists, psychiatrists dentists and nutritionists, who attend clinics in major regional centres. Working together as a one-stop shop resource partly funded by health and in part funded by disability services.

Although directly, health is not part of the CSTDA, it cannot act as separate units, for best outcomes, for community equity.  
Currently there is no equity in disability health as there are so few services.

Aged related disability have specialised clinics, they have specialised nursing, they have a raft of avenues to turn towards in seeking answers to physical problems as they arise.

***People with an intellectual disability far too often have their physical problems and mental illness overlooked, sometimes for decades, indeed it is difficult to find a medical practitioner who will even refer them on.***

Some of these studies below are over 12 years old. They can be found on the net, **SADLY 12 YEARS ON LITTLE HAS CHANGED.**

Lennox N (2002) Issues Paper - National Health Priority Targets for Adults with Developmental Disability  
Developmental Disability Unit, Faculty of Health Sciences, University of Queensland

Scott A, Marsh L, Stokes ML (1989) "A survey of oral health in a population of adults with developmental disability: comparison with a national oral health survey of the general population" ADJ 43; 257-261

Stewart L, Beange H, McKerras D (1994) "A survey of dietary problems of adults with learning disabilities in the community" Mental Handicap Research 7, 41-50

Beange H, McElduff A, Baker W (1995) "Medical disorders of adults with mental retardation: a population study" AJMR 99: 595

Bittles AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ, Montgomery PD (2002) "The influence of intellectual disability on life expectancy" J Gerontol A Biol Sci Med Sci 57:7; M470-M472

Department of Health UK (2001) Valuing people: a new strategy for learning disability for the 21st century  
Chapter 6, "Improving health for people with learning disabilities"

US Department of Health and Human Services (2002) closing the gap: a national blueprint to improve the health of persons with mental retardation [www.surgeongeneral.gov/library](http://www.surgeongeneral.gov/library)

Community Services Commission (2001) Disability, death and the responsibility of care (A review of the characteristics and circumstances of 211 people with disabilities who died in care between 1991 and 1998 in NSW)



## RECOMMENDATIONS

- *THE Commonwealth State & Territory Disability Agreement should not be renewed in its current form. The blame game must cease.*
- *The Federal government should commit to a National Standard of service minimums, removing the barrier of an artificial age divide.*
- *Disability services and funding must consider the life opportunities of the unpaid carer as well as the person with disabilities.*
- *Disability services nationally need an immediate target growth of 100% with a further 10% ahead of CPI over the next 10 years.*
- *Dept of Health and Disability Services must work together for better health outcomes. People with disabilities need speciality hospitals working in conjunction with accessible travelling clinics for regional areas with health care workers trained in disability health care and disability mental health.*
- *The Federal Government should commit to an equal partnership with states and territories that sets nationally benchmarked targets for services in all areas, across an entire lifetime, to produce opportunity for life quality and social equity.*

**OR**

- *The Federal Government should take full responsibility for the care and funding of services of Australia's most vulnerable, people with lifelong disabilities.*
- *All services should have benchmarked target minimums, along similar lines to that of aged care.*

***DISABILITY SERVICE AGREEMENTS HAVE TO STOP BEING ABOUT "SPIRIT" AND "INTENTIONS".***

***SERVICES MUST BE ABOUT SOCIAL EQUITY, INCLUSION & REAL LIFE OPPORTUNITIES FOR ALL.***