National Carers Coalition

Walk a Mile in My Shoes

Submission
to
Australian Senate
Community Affairs Reference Committee

Inquiry into the Funding and Operation of the
CSTDA

28 July 2006

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The National Carers Coalition welcomes the Senate Community Affairs Reference Committee Inquiry into The Funding and Operation of the CSTDA and thanks you for the opportunity to inform the Inquiry via the following submission.

Our document is the result of the collaborative effort, and lived experience, of a number of family carers. This submission expands on issues raised in our previous submission to COAG regarding the CSTDA. For your further information, we recommend that you read the COAG submission and accordingly we have forwarded that document for your attention as an attachment to this Submission.

We urge you to carefully consider both the perspectives brought to this Inquiry by family carers and the recommendations made for redress.

Yours Sincerely,

Felicity Maddison AM
Queensland Coordinator
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THE FUNDING AND OPERATION OF THE CSTDA

"The system will work better under one level of Government"

Foreword:

Created, and driven wholly by unpaid family Carers of people with dependent disabilities the National Carers Coalition (NCC) joins thousands of caring families in a common belief. 'There must be radical reform of disability services throughout the nation in order that long suffering families may find relief from unrelenting burdens of care.'

The NCC has its beginnings in the very public Walk a Mile in My Shoes Campaign commenced in the second half of 2005. On September 13 of last year hundreds of people participated in the *Walk A Mile in My Shoes* day across the nation. This day of action evolved out of the on-line discussion which took place after the ABC Four Corners TV Documentary on unpaid caring '*The Hidden Army' story* . More than 1,400 pairs of worn out shoes were placed on the lawns in Canberra and similar demonstrations occurred in Victoria, South Australia, NSW, QLD and WA where state and regional rallies were held concurrently.

The overwhelming view of families supporting the WAMMS Log of Claims was a call for a complete review of both the failed CSTDA and community mental health support systems. These calls were expressly for the Commonwealth Government to take responsibility for all its citizens and to remedy the disgraceful failed disability services system that exists today.

The release of the Mental Health Council of Australia Report in October last year, which also called for the Commonwealth to take leadership in the provision of services and support for people with a mental illness, saw the Federal Health Minister Tony Abbott being quoted as saying "the system would work better under one level of government". The Young People in Nursing Homes campaign has also called for such a leadership role from the Federal Government. We reiterate the Carers call for the Commonwealth Government to take responsibility for all citizens with a disability and for the unpaid family Carers who today feel abandoned by the state based system of disability services.

The myth perpetrated by the establishment; that unpaid family caring is a noble and appreciated vocation in life for those families saddled with this burden unaided, must be exposed. If decision-makers are to look with open eyes at the failed disability support system, they must look at what has become of the sham that is the 'community inclusion' rhetoric of the 'system' and expose it for what it is.

The NCC made an initial submission in November 2005, to the Commonwealth Heads of Government (COAG) for an urgent review of the CSTDA. That submission is particularly relevant to this Inquiry and will form the basis of our Submission to the Senate Community Affairs Committee; a copy is attached to this submission as attachment 1.

In making this submission, we inform the Community Affairs Committee that our struggle to 'be heard' is perpetuated by the absence of any funded disability family advocacy and support service. We most strongly resent this discrimination against caring families of persons with dependent disabilities who are aged less than 65 years.

Such gross failure to support caring disability families with a funded advocacy service is a clearly deliberate strategy, since the Disability Advocacy Review of 1999 and the later National Family Carers Voice Committee (set up by the then Minister for Family and Community Services) both strongly recommended it. In 2006, nothing has changed. We are denied the same privileges as are enjoyed by disabled persons themselves through a network of national state and regional advocacy services and by the aged care sector through their funded carer Associations. The lack of funding for caring disability families issue is particularly irksome to the 67% cohort of caring families of Australian adult citizens with disabilities who sit isolated in the 18 to 64 year age bracket.

It is also true that there is an absence of a nationally funded system of family advocacy for the parents of children with disabilities although one or two states endeavour to fund this critical need.

Hampered in our resources to put our case for urgent reform of the CSTDA, we never-the-less make the strongest possible submission for the Commonwealth to assume full responsibility for all its citizens with a dependent disability and for the families who care for them.

The NCC urgently seeks:

- An end to age discrimination in the delivery of disability support services.
- An end to discrimination in living choices that is open to people with disabilities.
- An end to the violation of citizenship rights for caring families.
- An end to the exploitation of unpaid family Carers as free care labour.
- An end to the exploitation of families as life-long providers of free accommodation to disabled kin.
- An end to the lifelong suffering of aged parent Carers for whom there is no reprieve from servitude.
- An end to the poverty trap for families denied the right to paid work because of the burden of care.

Wherever it is possible, we will expand upon our submission to COAG and we will make recommendations as to what needs to happen in the Review if unpaid family Carers are to have their due ‘Mutual Obligations’ met by the Commonwealth and the people of Australia.

We intend to use the words of family carers throughout this submission in order that Senators and other readers will know that this submission speaks from the heart of grass roots caring. We seek to ‘break the silence’ on the exploitation and neglect of hundreds of thousands of Australian families who do not receive a fair deal from the government of the people or society that owes them a debt it cannot repay.

William says: “ I am convinced that the systems relating to the disabled and unpaid Carers, are so flawed, that I feel compelled to resist... we all know we have the rough end of the stick, and as I see it, now is the time to start doing something about it. Are we going to let governments continue to act as they do or are we gong to make an Australia-wide noise for them to listen and act? ‘It is a matter of pressure’.... cars....weather....blood....water...electricity.. cappuccino, all respond to some kind of pressure... politicians also respond to pressure (votes and public) maybe the same pressure would help solve the desperate needs of the disabled and their unpaid family Carers .... To me the 1990’s had a sort of excitement, there was I thought, some motivation in endeavouring to achieve better conditions for people with disabilities! But, now (2004) the motivation and excitement and idealism are no longer apparent..... The economic rationalists have shifted the positive vibes away from people, to bureaucratic systems, which in reality is a dehumanisation of human services’.
‘Increasingly, crucial decisions regarding policy are made by people whose empathy and knowledge of a relationship with people with disabilities and their families is tenuous at best.’ Another impediment to the effective implementation of social policies is the high level of discontinuity, of both personnel and policies, in many organisations, community services, etc. Health services and government departments seem to restructure every 18 to 24 months.... I learned in my paid work-life that we tend to confront any difficult or new situation, by re-organising, which in reality is a great method of creating the illusion of progress, but, produces confusion, inefficiency and demoralisation.” [75 year old parent carer still waiting for a home for his daughter]

The NCC agrees with William; it is time to stop shifting the goal posts on disability services and support to caring families. It is time to take a quantum leap into the 21st Century by removing barriers to citizenship and removing discrimination based upon age. Most importantly is now time for the nation to meet its ‘Mutual Obligation’ to unpaid family Carers who are bearing the burden of supported accommodation for dependent Australian citizens almost entirely alone.

We express our gratitude to the Senators who supported the Carers call for this inquiry. It is our prayer and hope that you will hear our voices, consider carefully our concerns and resolve to fix the failed disability services support system. We ask for our sake and for the sake of future generations of citizens with dependent disabilities for whom the future of unpaid family care is bleak.

The National Carers Coalition would welcome the opportunity to have a delegation meet with the Senate Community Affairs Committee in Hearings about this Review. We trust that justice will prevail with the Government of our people to stop the exploitation of family Carers and take responsibility for our most vulnerable citizens, those with dependent disabilities for whom we care.

Thousands of Carers shoes on the lawns of parliament house the tags pleading to all politicians for social justice and a fair deal for families caring for disabled kin.

THE FIRST REAL ANSWER – POPULATION BASED BENCH MARK FUNDING

The Federal Government-managed Aged Care System of accommodation and support services for people aged 65 years and over relies upon a schedule of bench-marked funding increases to ensure that services meet the needs for aged care. This system is based upon a not too clear formula for growth funding, which currently funds service increases to maintain a ratio of 103 operational places and packages per1000 of the population aged over 70 years, per annum. The planned ratio will increase to 108 places per 1000 population per year, over the next four years as part of the Commonwealth aged care strategy. [Dept Health & Ageing Fact Sheet 2005]

By stark contrast the CSTDA operated by the states and Territories is without any growth policy at all, relying upon departments to go cap-in-hand to the treasury on an annual pilgrimage and to the Commonwealth every few years.

- It is a continuous ‘bun-fight’ between the states and the federal government over crumbs off the Budget Table for disability services in a feed the chooks mentality of lack of care for people with disabilities.
- There is no formula as the foundation for providing needs-based service increases and therefore no formula as the foundation for population-based bench-marked funding of services.
- The future of disability services is unrelentingly grim, ageing parent-carers are struggling to cope and there are increasing numbers of persons with dependent disabilities who should be in their own supported accommodation facing eminent homelessness as parent Carers die.
- Younger parent carers are struggling to cope with increasing severity of disability amongst sons and daughters who may previously have died.
- Increases in disabilities such as autism with behavioural implications, and increasing financial stresses and work demands in the era of the two-income family.

We require an entirely new approach to the funding and provision of disability support services, which recognises the absolute responsibility of government to “Plan, Fund and ensure the Provision of services to persons with dependent disabilities. In order to address the longstanding unmet needs pervading the current failed system, we require the introduction of Population-Based Benchmark Funding that Legislates to address that unmet need in the first instance and then adopts a benchmark that will be sustainable in the long term and which ‘is seen to be’ eliminating the aged-based barriers that pervade the current system.

The scope of the issue of population-based benchmark funding would seem to be overwhelming if it were to be applied in the same manner as that which currently exists to fund aged care, i.e. 103 places/packages per 1000 of the population aged 70 plus adjusted annually. This allocation is currently as set out in figure1. below :

Fig1. Table 12A.1 Report of Gov Services 2006

Pop 70+	% of total population	103/1000 benchmark for bed places /packages
1,892, 800	9.3	194, 958 places/ packages (a)

(a) aged care allocations currently = High care 40.8%, Low care 42.4%, CACP’s 16.0% and EACH 0.9%

To apply the aged care benchmark to adults aged between 15 and 64 who make up a 67% cohort of the general population we would come up with staggering figures as illustrated below using a simple 100/1000 benchmark.

Fig2. Benchmark funding allocation 15 -64 based on ABS – DAC 2003 chart-4430.0

Pop 15-64	% of total population (b)	100/1000 benchmark for bed places/packages
13,273,437	67	1,367,000 places / packages (rounded)

(b) based on 15-64 population of-19,811,100

Are the figures above too staggering to contemplate, well then, we will next apply the severe and profound incidence facto to the under 65's benchmark as follows:

- The over 70 years of age incidence rate of sever/profound population is currently 22.5%.
- The 15-64 years of age incidence of severe/profound is relatively static on 3.9% of the total population.

Comparing the over 70 years of age incidence of sever/profound of 22.5% with the 15-64 years incidence of severe/profound of 3.9% we create an incidence ratio of 5.7 / 1. That is 5.7 units or care packages for 70+ population to every 1 unit or care package for the population age range of 15-64; meaning that the disability support sector benchmark should be 18 /1000 of the population aged 15-64 years and that would look like this:

Fig3. ABS – DAC 2003 chart-4430.0

Pop 15-64	% of total population	18 /1000 benchmark for bed places/packages
13,273,437	67	238, 914 places / packages (rounded)

Clearly, the funding of such a formula for disability services would require a 'quantum shift' in current policy, planning and commitment. This is seriously exactly, what we are asking government to do. Justice demands it!

There has to be a sustainable formula for benchmark funding of disability support services, which will address unmet need and decades of neglect in the funding of disability services. We therefore propose a transitional plan to introduce benchmark funding based upon the **potential population only** as set out in the CSTDA-MDS 03-04.

To this; we will apply the above benchmark ratio as a basis for funding growth per year for a period of five years at the nominal benchmark of 18 beds/packages/1000 as a growth / year proposal as follows:

Fig. 4. Benchmark funding based upon 18/1000 potential population 0-64 CSTDA-MDS 2004

Potential Population CSTDA-MDS 03-04	18 /1000 benchmark for bed places/packages
687,710	12,366 new services per year for five years

This funding will increase the number of beds/packages by 61,830 over five years across the nation. The increases will be based upon the same or similar ratios to those in aged care. i.e.

- High care beds/packages 40%
- Low care beds/packages 40%; and
- Community Access packages 20.0%
- Each category will allow for facility based and home-based respite as a priority.

There is an urgent need to support distressed families who have waited far too long for alternative accommodation options for loved ones. Applying a five year urgent catch-up will remove most persons from urgent out-of-home supported accommodation waiting lists and provide intensive in-home support to frail aged and highly distressed families.

Thereafter, increased funding for accommodation and support services at a Benchmark rate of 18/1000 of the population aged less than 65 should be introduced incrementally, along with the above standard increases until catch-up has occurred.

There will clearly be a need for substantial capital funding for new and innovative facilities to match the growth rate and reform of disability services into more cost effective models and choices of accommodation and supports than currently exist.

It is our intention to convince the Senate Community Affairs Committee to take immediate action on this urgent reform proposal in order that all citizens with a dependent disability and the families who care for them will receive equal access to supports and services, which eliminate age discrimination and meets national mutual obligations standards.

CSTDA - FAILURE ON ALL LEVELS OF SERVICES DELIVERY

The Creation of An Underclass Never Before Seen In Australia.

While everyone acknowledges that early intervention is crucial to the best of life outcomes for children manifesting disabilities and behavioral disorders, the support reality is at extreme odds with the knowledge and the spin. Across the nation families report that the time delay from applying for help and support by families to actually receiving these supports is appalling. The wait for assessment of need can be 6 months to a year, even longer in some cases. Once assessed, the service delivery often takes so long to implement that the child needs reassessment to even begin the intervention. Years long, waiting lists following assessment of need are systemic. All too frequently, families wait 2, 3 or 4 years for basic behavioral strategies, speech therapy or occupational therapies. Often the child is of school age and still waiting for basic services, applied for as a toddler. Georgia, a single mother of two children with autism said that she was on the intervention list for 3 1/2 years:

> *“If it wasn’t for my sons school principal screaming at the service, I don’t know how long I would have waited for support. It seems that the power of the school system is all we had going in our favour. Years of my pleas fell on deaf ears, but our irate principal was able to get the assistance my son required”. I cannot help but wonder where he would be in his development if we had have received support, guidance and a planning strategy when we first sought it.*

Dual Diagnosis under the CSTDA is a life sentence - say parents:

> *"My daughter who has a moderate intellectual disability with a degree of autism developed schizophrenia in her late teen years. All of her life, every bit of support for her (which has been very little), has been a battle to obtain. This has broken me as both her mother and her Carer. I called my local services office and explained the critical need for support with the behaviors she was showing and was put on a behavioral intervention list. In a distraught moment after a 14 month wait I called yet again to find that my daughters name been removed completely from that list sometime between phone calls (they could not/would not explain why) and I was told to reapply.*
> *Over the past 19 months, I have watched 19 years of work and dedication fly out the window as her behavior, her friendships and her self worth, have sunk into a sea of despair. No one will help us, mental health said they did not have the resources to assist her because of the intellectual disability and the ‘so called’ disability services had not one service or support for the dual diagnosis of intellectual disability/mental illness. If we eventually get intervention, it will take years to change the now habitual behaviour problems, when strategies placed in a timely manner would have stopped the regression. A stitch in time would have saved nine; it is totally false economy to let it go so long. Frankly, unsupported and alone with this, my life is not worth living, the burden of being so alone with so little support and nowhere to turn , his last straw has finally broken me!"*

Many families facing the dilemma of dual disability tell us of their struggle to get professional help and that:

- There are few psychiatrists in Australia whose practice focuses on intellectual disability and mental health as a dual disability. (one Sydney psychiatrist has a practice that extends across most of the state, down to the Victorian border and across into Tasmania!)
- The highest population based rates of mental illness are in this cohort, running at 30-40% (these figures are arguable as much mental illness is misdiagnosed due to the complications of articulation, of medical disinterest, and misdiagnosis in the moderate/severe/profound intellectually disabled.
- Mental health issues are scarcely recognized under the CSTDA as needing specialised supports, nor are they appropriately serviced under Health.

Intergovernmental and interdepartmental response to the health care needs of people with intellectual disabilities is dysfunctional at best and shows a callous disregard for these citizens at worst.
Cancer patients have their own defined services, as do children, as does practically any other illness or disability. For those presenting with intellectual disabilities it is an ad hoc system of searching here, searching there, searching everywhere, only to be let down by medical and bureaucratic indifference, often being turned away under the misguided view that disability services are all that are required.

We are failing the disabled on a massive scale with all levels of health care.

A study by the NSW Council for Intellectual Disability concluded that: At the State level, there is one specific initiative that is a top priority. There needs to be a resource in each Health area that can:

* Undertake diagnostic assessments of the health care needs of some individuals with complex medical conditions. This would be on referral from a general practitioner.

* Provide advice and training to doctors and other health and disability professionals.

* Foster the development of better local networks.

This resource should take the form of an intellectual disability health resource team. This would be a multidisciplinary team that includes a doctor who specialises in intellectual disability and professionals in nursing, dietetics, speech pathology, neurology, psychiatry and alcohol and other drugs. For full paper - http://66.102.7.104/search?q=cache:Io7I2vTCvlYJ:www.nswcid.org.au/systemic/position

* The life expectancy of a person with an intellectual disability is approximately twenty years lower than the general population. (Bittles &others 2002)

* In Northern Sydney, 42% of medical conditions went undiagnosed in people with intellectual disabilities and half of the diagnosed conditions were inadequately managed. (Beange & others 1995)

* Obesity for people with intellectual disabilities is up to three times the level in the general population. (Stewart & others 1994)

* 42% of 211 people with disabilities who died in care were underweight and some died because of critical illnesses being untreated (Community Services Commission 2001)

* Dental disease was up to seven times more frequent than in the general population. (Scott & others 1998)

THE INEQUALITY OF FAMILY CARE 'V' ALTERNATE CARE

Many carers we spoke to in the course of preparing this submission brought up the differences between unpaid carers of children with disabilities and paid foster carers of children with disabilities.

> *" I cannot get services for my son, everything is a battle, I have about 16 nights of respite per year and I receive a whole $93.00 per fortnight from the government as carer's allowance which pretends it pays me. I live in poverty with little hope on a sole parent benefit, unable to work enough to offset the costs and losses which could make working worthwhile.*
> *If I gave my son up to the state, the foster Carer would/could access heaps of respite, basically, she could name the amount she needs. As a foster child, my son would have all therapies and interventions when, and as my son needed them. The foster Carer would receive any carer's benefits that I receive, as well as a payment of hundreds of dollars for being a foster Carer. Whilst receiving these supports the foster Carer could work full time and not lose any of the money, unlike me who would have earnings reduced to practically nothing. In fact I am probably being selfish keeping him, he would have a better chance to be as good as he can be if I gave him away."*

This is in fact a true experience; children with disabilities have a far greater chance of accessing services and opportunities if they do not live with their natural parents and that it is not only in the childhood years that these discrepancies appear.

This blatant bias against the natural family was highlighted on the 12th July 2006 in Victoria's Herald Sun with a feature entitled: "Bureaucratic madness could force a disabled teen into an institution, says angry mum". This article is worth reading, it shows the inequities of services for natural born children with disabilities and those either adopted or fostered. This single mother fostered, then adopted a child with disabilities. She works full time has in-home Carers for 7.30am to 7.30pm in a package worth $123,000 per year according to the acting Community Services Minister. The mother's complaint was that now her adopted child had turned 18 her generous Foster Carers allowance of $175 per week was being stopped. http://www.news.com.au/heraldsun/story/0,21985,19761561-2862,00.html

The writer knows of no examples where the same levels of services are given to the natural parent in similar circumstances. We believe that all families raising children with disabilities and continuing that care into the adult years deserves the same level of commitment by governments, albeit with needs assessment.
This message was articulated by a parent Carer whose response to the Herald Sun article was printed in the 'you say' section with the title- **Carers are the new slave labour:**

"JANE Hickey is to be commended for choosing to raise a disabled child through fostering and adoption ("Save my son", July 12 2006). She is a victim of the same insidious bureaucratic stupidity that gives lip service to community inclusion for disabled people. Families are forced to give up disabled offspring to foster carers because they don't get the same level of support offered to people such as Jane. The bureaucracy is killing caring families and everyone is looking the other way. There are at least 165,315 Victorian families caring for a dependent relative under the age of 64. These people are waiting for help and getting virtually nothing.

More than 13,900 of these parent carers are still caring for adult children aged over 33 years who have a severe or profound disability. More than 4200 of this group are waiting for urgent supported accommodation or intensive in-home support. They wait in vain because Victoria has stopped building group homes and put nothing in their place. Aged parents are dying in despair every day and no one seems to give a damn.
Jane Hickey at least has support so that she can go to work - 75 per cent of full-time carers are women denied any access to paid work because there is no support service for any of them. Jane deserves all the support she has, and so do all the natural families stressed to breaking point who have none. Stand up Victoria and say no to a shameful Government that kicks caring families in the teeth for saving taxpayers over $10 billion a year in Victoria alone, by caring without any support at all. Slave labour is alive and well in the brave new 21st century. parent carer 40 years and counting."

It might well be argued - that because we love, care for and support our children, by keeping them within the family structure, we are denying them possibilities by default, simply because governments view unpaid carers and the children/adults with disabilities of unpaid carers as expendable. The evidence of a system in crisis is everywhere. Again we draw on reports out of Victoria because all jurisdictions seem to think that Victoria is doing a better job under CSTDA that the rest of their counterparts, but are they! The media continues to pick up on these stories of despair.

FAMILIES DRIVEN TO DESPAIR ARE INCREASING IN NUMBERS

Parents dump disabled kids - Herald Sun Report - Susie O'Brien, social affairs reporter - 28 March 2005

DISABLED children are being taken to weekend respite centres and not picked up again as desperate parents reach breaking point. Forty Victorian children are living permanently in short-term accommodation after being relinquished by their families, according to the State Government. The Association of Children with a Disability said it could be as many as 100. A shortage of foster carers and complex disabilities mean it can take years to find these children new homes. Some families struggle on at home for years waiting for foster homes. Two families in Cheltenham and Bulleen have waited four years for new homes for their children. Mother Anita Fejzullai has asked the Herald Sun to help find a loving foster family for her daughter Emine, 14, who has partial chromosomal trisomy, an intellectual disability and epilepsy. She has spent the past two years at an interim centre in Coburg, which has been a good, stable base but not a home. "I just want someone who will look after her and love her like I do. She's a lovely girl and a very happy girl," Ms Fejzullai said. "But I'm by myself with no family and friends to help me and I find it very difficult to look after her." Yooralla manager Marisa Harvey said parents failed to collect their children from respite care "only in extreme cases . . . but it does happen". "There are families who are very stressed and extra resources are needed to support them in terms of better access to respite care and other appropriate support services," she said.'

Much fanfare was made of the recently released NSW 10 year plan with it's commitment to 1000 places of supported accommodation over the next five years. What was not loudly lauded was that most of these placements have been earmarked for young adults who have been in the care of foster families. Once again the unpaid family Carer and their children are being relegated the dustbin of disability supports and few will be thrown any scraps.

Nevertheless, we encourage the NSW Minister for Family and Community Services for taking the 'first step' upon a road un-traveled. The road to a just and sustainable system of disability support services. We expect all state Ministers as our elected representatives to also hear the cries of the families articulated here.

Joyce is in her late 70's, her son is 56, and Joyce has been a full time unpaid caregiver for 56 years. Sadly, Joyce was widowed a few years back and she has been left to struggle alone with her son who is very demanding, he has a moderate intellectual disability and also suffers from a mental illness. Joyce, a recent breast cancer survivor, is still waiting for supported accommodation for her son. She was told a year ago that she was high up on the emergency list.
Does Joyce have to die in her bed before help is at hand? Is this how Australia treats it's aged, if they happen to be unpaid Carers? Joyce receives aged care services for herself, but paradoxically she continues to care for her son whilst the department of ageing cares for her.

Yet another Carer writes:
I have a friend who developed breast cancer; she is a sole parent Carer. When she was hospitalized for surgery, her mother was supposed to care for her 16 year old son. Her mother, wise to the ways of government, unbeknown to my friend, sent her son off to respite care, saying she could not cope. When my friend came home from hospital, she was too sick to bring him home. She came to realise, with the support of her mother, that her son was happy and that this was her opportunity – it might never come again, so she decided to refuse to bring him home. He stayed in respite care for 8 months, finally the government realized she could not be manipulated into taking him back and found him a permanent placement.
*She now has him stay some weekends, she can visit him whenever she likes, she has a thing called a social life, she is employed for the first time in years and she is really glowing with health and happiness. She says she has become a **'normal' person.** I wish that I was so brave, I wish I was a **'normal person'**, I am so paralysed by fear of the unknown, fear of the future for my adult daughter, I do not know if I will ever be brave enough or strong enough to seize the day. I fear that by that time, I will be so old and tired I will not be that same healthy, happy, glowing person that my friend has been able to become. I know that perhaps I will have to make my own opportunity to do something similar one day; it is the only way help happens. How sad, I will have to abandon her, 'dump' her to ultimately do what is best for he and for myself. At least I now know that it can have a good ending, that bravery on my part, will allow my daughter the opportunity to live a normal adult life, not stuck at home with an aging mother, but living with her peers, doing aged appropriate activities. Sometimes I really believe that death would be a blessing, sometimes I am overwhelmed with pain, with feelings of impotence and no-one seems to care. **I feel so alone.***

These cries for justice cannot be ignored any longer.

The Need for Substitute Care – Balancing work and Disability Caring

The majority of submissions to the recent "Balancing Work and Family" Inquiry identified **families** as those caring for children aged 0-12. The submissions also identified that alternate/substitute child care is required in order that families can enter/re enter the paid workforce. The type of childcare required is based on the age and developmental stage of the child i.e. a baby will require assistance in all aspects of their life- protection, constant supervision and attention, feeding, changing because they cannot do this for themselves.

As developmental milestones are reached and skills of independence -such as speech, mobility, independent toileting and bathing, independent dressing, cognitive awareness and thought processing, likes/dislikes and the ability to express such choices, awareness of danger and the ability to discriminate- are acquired, there is a tapering in the intensity of care required culminating in a developmental stage of life where acquired skills of independence result in care where minimal supervision and direction is required.

Submissions called for increased availability of **substitute childcare**, school holiday programs, and pre and after school care as a stated necessity for family participation in the paid workforce.

In chronological adulthood, where all developmental milestones are presumed to have been reached, the expectation is that, as adults, there should be no need for assistance from another person to provide support/assistance in the activities of daily living or in decision making. Therefore, **it is the Dependency and Vulnerability** of the child, based on developmental levels, that is the criteria for substitute child care. Substitute childcare attracts both family taxation rebates/offsets and childcare subsidies that are applied nationally through the Commonwealth Government, enabling families' to freely move intra and inter state without loss of substitute care.

The CSTDA now actively acknowledges families supporting children with a disability and ageing carers aged over 70 and specifies these groups as targets for supports under the CSTDA. CSTDA initiatives now include early intervention, after school care, school holiday programs and respite for families caring for children with a disability and family carers aged over 70 caring for an adult with a disability. The targeting of younger families caring for children with a disability is acknowledgement that without these interventions families will experience the family breakdown/ dysfunction and loss of workforce participation experienced by the generations of families preceding them.

The Forgotten Families

This submission will introduce to you "**other" families –** families of **adult children with a disability** where developmental milestones have either not been reached or lost by accident, leading to **a static and lifelong dependency on another person for support and assistance.**

What is known about these "other" families?

- Prolonged parenting - their "parental care" role (24hrs/day 365days/year) extends for decades – 85 year old parents caring for sons and daughters with dependent disabilities aged in their late 50s and 60s
- No retirement from the caring role
- No "empty nest" as the normal patterning of adult children leaving home and leading their own lives does not occur
- Higher than the national average divorce rates coupled with lowered re-partnering rates leading to prolonged single parenthood and lowered workforce participation rates
- Mothers comprise the vast majority of single parents of (adult) children with a disability
- The lack of availability of substitute care/supports leads to long term dependency on income support for many family carers
- Poverty – a significant percentage of "other" families' income levels are in the lowest quintile
- Fractured and dysfunctional families – loss of extended family engagement, sibling impacts

- Limited access to supports and services once the person with a dependent disability turns 18 – resource deprivation for both the family and the person with a dependent disability after chronological adulthood is reached
- Limited or no portability of supports –i.e. local, regional or states boundaries create barriers and services/supports cannot be transferred to another locality, region or State. Only those with individual funding can move between regions or State wide without loss of supports. Moving interstate with individual funding is time limited and there is no guarantee that after time limits run out that future funding will be available.
- Ability to enter/re-enter the paid workforce for unpaid family carers is dependent on availability of substitute care for their adult children with disabilities
- Over 40% of primary family carers acquire a disability as a result of their care role
- Many family carers experience depression, isolation, and suffer from stress related illness
- Unpaid family carers generate savings to the Australian economy in excess of $30billion yearly.

The CSTDA is not addressing the needs of those families who have not received the benefits of being supported throughout the years; the impacts of this neglect are outlined above. There is no acknowledgement of the impacts on families of adults with a dependent disability (not until you reach 70).

- The need for regular respite and holidays.
- The need for substitute supports to escape welfare dependency and enter/remain in the paid workforce.
- The need for meaningful social interactions outside the family home.
- The need for as ordinary a life as is possible – including the choice to end the prolonged parenting role where families of people with dependent disabilities are locked into providing the primary care for their family member with a disability beyond an age when it is reasonable for them to be required to do so.

People with a disability and their family carers have a right to support to lead normal lives and make normal life transitions at an age appropriate point in the life cycle. All families need and deserve to have a break. Respite services and supports play a vital role in alleviating pressures on primary carers and other family members. Regular and appropriate breaks - including holidays away from the caring role- contribute to family wellbeing/ rejuvenation, a decrease in the social isolation created through the intensity of the care role, and facilitates “de-stressing” periods for primary carers.

Respite for family carers should never be confused with supports for the people they care for i.e. a day support service for an adult with a disability is NOT respite for the primary Carer. Unless a substitute support is placed in home to undertake, the work that the primary Carer does in the home in support of a person with a dependent disability no respite occurs. Primary carers should not have to contribute unpaid supports for 40, 45, or 50 years (until they reach the magical age of 70) in the care role before an entitlement to “up to four weeks of respite” per year.

Unpaid family carers should not have to work to the point of exhaustion or disability because of government unwillingness to appropriately partner with families in supporting adults with a dependent disability or to appropriately support adults with a dependent disability in a life outside the family home. The reliance on families to provide ‘informal support’ has resulted in a grossly unequal ‘partnership’ between governments and family carers.

It is estimated that over 90% of care and support in the community is provided by the “unpaid” sector. If every family Carer providing 24 hour care/support to a family member with a dependent disability contributes 90% of the care/support required; this means in every 24 hour period they are providing 21.6 hours of support. However, for many family carers the full 24 hour care/support role is a reality of daily life in an unrelenting 365 day/year unending cycle.

The Commonwealth Government through its National Respite for Carers Program (NRCP) acknowledges family Carers' needs for substitute supports in order to enter/remain in the paid workforce. The NRCP has recently introduced a Respite for Working Carers Program that is delivered nationally. However, access to this support is only available to **Carers of the Aged or Carers of a person with Dementia.** There has been no attempt to include unpaid family carers of people with a disability aged less than 65. **Why is this so?**

It is ironic that whilst governments find that it is age 'inappropriate' that adults with a dependent disability aged under 65 should reside in Aged Care facilities (24hour care) governments are singularly silent on the appropriateness of sons and daughters with dependent disabilities living with aged and ageing parents- parents who do not fit the criteria of age appropriate.

AUSTRALIAN CITIZENSHIP AND THE CSTDA

The National Multicultural Advisory Council defines 'citizenship' as a bond or glue, consisting of shared membership in a political community, that is, a commitment to the Constitution and the laws, the rights and obligations and the core values and practices of Australian democracy. At Federation in 1901, no legal category of Australian citizenship existed: 'British subject' remained the only formal civic status in Australia. The legal status of Australian Citizenship, defined in the Citizenship Act 1948, brought for the first time a distinct status of being Australian; however, it was not until 1984 that Australian citizens ceased to be British subjects' altogether. The expectation of the coincidence of citizenship and nationality – of membership and identity – was not fully realised in Australia until the 1980s.

Whilst existing Australian legislation identifies the responsibilities of Australian citizens to Australia as a nation state there exists no definitive statement of the rights bestowed by Australian citizenship. It is suggested that Australian citizenship is defined through a plethora of Commonwealth, State and Territory legislation which are based on a large number of instruments covering human rights, to which Australia is a party, and developed under the auspices of the United Nations. These instruments include the Universal Declaration on Human Rights (1948), and the Covenants on Civil and Political Rights and Economic, Social and Cultural Rights (1966) with their various protocols.

More specific instruments include the Convention on the Prevention and Punishment of the Crime of Genocide (1948), the Supplementary Convention on the Abolition of Slavery and the Slave Trade (1956), three Conventions on Nationality and Statelessness (1957–66), the Convention on the Political Rights of Women (1952), and the International Convention on the Elimination of All Forms of Racial Discrimination (1966). Freedom of religion, freedom of assembly, mobility throughout- and into and out of - the nation state, the right to vote, trial by jury, are just a few of the many participatory concepts commonly understood as integral to citizenship. However, it is suggested that Federalism complicates citizenship in Australia by splitting jurisdiction over many citizenship matters between the federal and state governments.

So if being a citizen is about participation, what happens if you can't participate in social, economic or cultural life?

Denial of the opportunity for social participation is in effect a denial of citizenship and as such, we believe that Australian citizens who are unpaid family carers and Australian citizens with a dependent disability do not enjoy the same citizenship rights as Australian citizens without a disability. The barriers to participation in the social, economic and community life of Australia experienced by unpaid family carers and people with a disability are well documented in research literature and have been previously discussed in this document. Governments' over-reliance on unpaid family carers to provide support without assistance and the apparent unwillingness of governments to enter into a full partnership of mutual obligation with families creates the barriers for family carers and people with a disability to fully participate as a citizen.

The CSTDA, by the very nature of its multi and bi lateral agreements, denies people with dependent disabilities and unpaid family carers the full benefits of Australian citizenship – they are instead regarded as citizens of a State or Territory who face a loss of supports (and lengthy waiting lists for support) if they cease to be a citizen of that State or Territory.

Adults with dependent disabilities require support to participate as citizens and unpaid family carers require substitute supports for the person they support in order to participate in the social, economic and cultural life of Australia. It is the issue of portability of supports throughout Australia that impacts on mobility rights -seen as a crucial factor to full citizenship for unpaid family carers and adults with a dependent disability.

Under the *Canadian Charter* and *European Convention*, (both inspired by the *Universal Declaration of Human Rights*) mobility is a right of citizenship for Canadian and British citizens as outlined as follows:

The Canadian Charter

The *Charter*'s unifying purpose was particularly important to the mobility and language rights. Through the mobility and language rights, French Canadians, who have been at the centre of unity debates, are able to travel throughout all Canada and receive government and educational services in their own language. Hence, they are not confined to Quebec (the only province where they form the majority and where most of their population is based), which would polarize the country along regional lines. The *Charter* was also supposed to standardize previously diverse laws throughout the country and gear them towards a single principle of liberty. **Mobility rights:** the right to enter and leave Canada, and to move to and take up residence in any province, or to reside outside Canada.

Benefits of British Citizenship and membership of the European Union

Britain joined the EEC in 1973, and is therefore a Member State of today's European Union. Citizenship of one EU Member State means that an individual enjoys the right of free movement of persons within the all the EU Member States. An EU citizen of one EU Member State does not need a visa, a residency permit or a work permit to go and live and/or work in any other EU country.

THE AUSTRALIAN CONSTITUTION AND THE CSTDA

The Australian Constitution passed as part of a British Act of Parliament in 1900 and took effect on 1st January 1901. This saw the joining of the States and two Territories (NT & ACT) into a federated government called the Commonwealth Government. Although the States and Territories retain autonomous governments within their own boundaries, the Commonwealth Government is generally regarded as the more powerful partner in the Federation of States and Territories that form the Commonwealth Government. It has been suggested that one of the main reasons for the movement by the Australian people towards federation was the desire to have a single trade area or 'Common Market' throughout Australia through the removal of protectionist burdens on interstate trade.

Section 117 of the Australian Constitution provides that

"A subject of the Queen, resident in any State, shall not be subject in any other State to any disability or discrimination which would not be equally applicable to him if he were a subject of the Queen resident in such other State."

This section was a reduced version of a clause proposed by Andrew Inglis Clark (Tasmania) modelled on the Fourteenth Amendment to the American Constitution dealing with the safeguard of individual rights.

It should be noted that the wording in S117 has not been amended since its acceptance by voting Australians in 1901. It is therefore arguable that the term disability was not a common usage word to describe people with impairment at that time, but was instead used to denote disabling or handicapping actions against Australian citizens.

We have previously discussed the barriers to mobility through lack of portability of supports - barriers created by the multi and bi lateral agreements that comprise the CSTDA and ***we believe that these agreements breach Section 117 of the Australian Constitution.*** Australia has NO Bill of Rights, however Australia is signatory to a number of United Nations Conventions as previously outlined. We also believe that both Government policy initiatives and discriminatory practice in resource allocation breaches a number of sections of The Universal Declaration of Human Rights as follows:

The Universal Declaration of Human Rights

Article 1. *All human beings* ***are born free and equal in dignity and rights***
Whilst Australian citizens may be born free and equal in dignity and rights, where a dependent disability manifests in the individual equality, dignity and rights disappear. There appears to be a lack of understanding, by both governments and the community, that in order to be equal, citizens with a dependent disability require support, usually that of another person. For unpaid family carers there is no dignity in being exploited because of familial ties.

Article 4. *No one shall be held in* ***slavery or servitude***
Unpaid family carers believe that when there are little or no supports available to Australian citizens with a dependent disability, families, out of necessity and under duress, are obliged to undertake the support/care role for members with a dependent disability. Family carers receive no wage for providing a support/care service despite the work that they do being the basis of a human service industry that employs and pays people to perform the same work. Unlike their paid equivalent, unpaid family Carers have no protection and entitlements set down in industrial laws.

Article 13 *Everyone has the* ***right to freedom of movement and residence within the borders of each state (for the purpose of the Declaration state means nation state)*** *-*
[see discussion on resource allocation and barriers to mobility and participation]

Article 16. ***The family is the natural and fundamental group unit of society and is entitled to protection by society and the State:-*** In Australia it appears to apply only if the family is caring for a child or a family member who is aged

Article 21. *Everyone has* ***the right to equal access to public service in his country:-*** discriminatory practice in resource allocation & availability based on age, denies equal access to public services to people with dependent disabilities aged less than 65 years, impacting harshly on caring families.

Article 23. *(A) Everyone has the right* ***to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment -***
(B) Everyone, ***without any discrimination****, has* ***the right to equal pay for equal work***
(C) Everyone who works has ***the right to just and favourable remuneration*** *ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary by other means of social protection:-* Clearly Unpaid family carers do NOT have favourable conditions of work, do NOT receive equal pay for equal work, and do NOT have favourable social protection.

Article 24. *Everyone has* ***the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay:-*** Unpaid family carers have **no** entitlement to rest and leisure, **no** limitation of their working hours and **no** periodic holidays with or without pay.

Article 29. *In the exercise of his rights and freedoms,* ***everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.***

There is NO justification for the limiting of the rights of family carers and their family member with a disability to pursue ordinary lives in our democratic and wealthy nation. The 'mutual obligation' rationale of economic rationalization, should mean a just reward for unpaid family Carers' annual contributions of $30billion to the national economy, but mutual obligation is glaringly absent from government's response.

As such, we believe there is a case for the Commonwealth Government to take action to remedy both the discrimination and disability that unpaid family carers and Australians with a dependent disability are subjected to as outlined previously. It is suggested that the Commonwealth Government assume full responsibility for the provision of supports and services to unpaid family carers and people with dependent disability aged less than 65. This should be done in order to comply with the Australian Constitution and in order to provide people with a disability and their unpaid family carers with the status of Australian Citizenship.

> *Shared supported facility based accommodation (CRU) should be available in every town (aged care have this luxury and choice) but our sons and daughters under 65 years can do what? --- yes !! stay at home with us -- where is the choice.*
> *We are prisoners until the day we die – old age and retirement will not be a joy for us!! As we have our adult disabled still at home – why can't we have part-time shared and supported accommodation provided by the government, at an affordable cost and locally? But guess what – once a "carer" reaches the age of 65, and you are on an Aged Pension, you are not eligible for a carer's annual bonus, even though you are still caring for your disabled person – how fair is that?*
> *Disability Services and programs need to continue, but government must provide adequate funding to service same, to provide adequate and safe care and environments for our sons and daughters to maintain a happy, safe, comfortable, affordable, useful and work opportunities within their own communities and abilities, just like you do in yours!*
> *Life-long Carer of twin adult children with severe/profound disabilities*

THE FAILURES OF THE CSTDA ARE READILY APPARENT

The failures of the CSTDA are readily apparent in the Minimum Dataset (MDS) figures produced by the Australian Institute of Health and Welfare (AIHW) for CSTDA funded services in 2003-2004. Although these figures are published in our COAG Submission, and freely available from the AIHW, it is worth reprinting them here for clarity.

The CSTDA MDS sets out comparisons between the number of persons in receipt of a funded service and the 'potential population' of persons with a severe or profound disability aged 64 and under. The potential population is derived from the ABS Disability Aging and Carers Survey of 2003. This survey confirms previous incidence rates of severe and profound disabilities within the population aged less than 65 as 687,710 persons or 3.9%.

Note: that although the MDS comparisons are targeted to a potential population of persons with a severe or profound disability; a significant number of CSTDA service users had a moderate disability i.e. Accommodation support users – moderate to no disability equalled 9.2% nationally. (Report on Government services 2006 Table 13A.13)

The CSTDA-MDS figures are of greatest interest to this Inquiry, not for the number of persons in receipt of a CSTDA funded service, but, for the number of citizens who DO NOT HAVE ANY SERVICE AT ALL.

Figure 5: Service users per 1,000 ‘potential’ population by service group, for CSTDA funded services by state and territory, 2003-2004.
Table also shows the number of persons who did not receive a service in each category of CSTDA responsibility!

Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
	Accommodation support								
No. of service users	6,440	12,989	4,933	3,136	4,069	1,069	334	212	33,175
Potential population	229,183	165,315	134,671	69,074	52,114	17,004	11,248	8,986	687,710
Service users/1,000 potential population	28.1	78.6	36.6	45.4	78.1	62.9	29.7	23.6	48.2
Have NO Service - potential population	**222,743**	**152,326**	**129,738**	**65,939**	**48,045**	**15,936**	**10,914**	**8774**	**654535**
	Community support								
No. of service users	18,013	28,485	8,564	11,138	9,916	2,173	188	509	78,847
Potential population	229,183	165,315	134,671	69,074	52,114	17,004	11,248	8,986	687,710
Service users/1,000 potential population	78.6	172.3	63.6	161.2	190.3	127.8	16.7	56.6	114.7
Have NO Service- potential population	**211,170**	**136,830**	**126,107**	**57,936**	**42,198**	**14,831**	**11,060**	**8,474**	**608,863**
	Community Access								
No. of service users	6,483	18,441	5,354	10,354	4,827	1,493	419	286	47,636
Potential population	229,183	165,315	134,671	69,074	52,114	17,004	11,248	8,986	687,710
Service users/1,000 potential population	28.3	111.6	39.8	149.9	92.6	87.8	37.3	31.8.	69.3
Have NO Service- potential population	**222,700**	**142,875**	**129,317**	**58,720**	**47,287**	**15,511**	**10.829**	**8,700**	**640,074**
	Respite								
No. of service users	**4,153**	**8,607**	**3,306**	**2,464**	**1,390**	**238**	**255**	**155**	**20,547**
Potential population	*71,075*	*51,205*	*41,819*	*21,402*	*16,211*	*5,308*	*3,478*	*2,761*	*213,298*
Service users/1,000 potential population	58.4	168.1	79.1	115.1	85.7	44.8	73.3	56.1	96.3
Have NO Service- potential population	**66,922**	**42,498**	**38,513**	**8,916**	**14,821**	**5,070**	**3,223**	**2606**	**192,751**
	For comparisons the Commonwealth managed Disability Employment Services								
No. of service users	19,003	18,283	12,036	6,217	5,911	1,667	898	410	64,281
Potential population	108,235	79,161	64,707	34,066	24,789	7,388	6,104	4,379	328,677
Service users/1,000 potential population	175.6	231.0	186.0	182.5	238.5	225.6	147.1	93.6	195.6

Accommodation support - slight of hand reporting:

- Overall, more than half (51%) of accommodation, support-service users received support to live in their own or family home – services included attendant care, personal care, and in-home support. Furthermore, more than half 51% of accommodation support users also received community access services.
- 6,472 CSTDA funded service users identified that their informal carer was aged 65+
- Only one third (33%) of accommodation support service users were provided with accommodation in group homes.
- 16% were provided with accommodation support in institutions or hostels.
- Over 14,000 (42%) of the 33,175 accommodation support service users also received community access services such as learning and life skills development, recreation and holiday programs.
- National average costs for accommodation support services are as follows:

Institutions and hostels:	$74,461 per service user
Group homes:	$83,098 per service user
Community based support:	$18,883 per service user

It is readily apparent from the minimum dataset figures that the CSTDA is a completely failed system in meeting the needs of persons with a severe or profound disability (S&P).

- No-one could possibly argue that 4.8% of persons with a S&P disability having accommodation support is a great outcome.
- No-one could possibly arguer that 11.5% of the potential population having community support is anything other than a disgrace.
- Community access for just 6.93% of the potential population is just as woeful.

This prompts the writers of this submission to ask who in fact is looking after the rest of these people who rely on others for their daily existence.

THE CONTRIBUTIONS OF FAMILY CARERS IN THE CONTEXT OF THE CSTDA

To put the contributions of unpaid family caring into perspective in this equation of who does and who does not have access to a CSTDA funded Disability support service is to lay open and expose the exploitation of family members as carers. This exploitation is sanctioned by all levels of government, service provider peaks and shamefully also by disability advocacy, all of whom are very willing to perpetuate the status quo!

A 'customised' set of Data from the ABS 'National Survey of Disability Ageing and Carers 2003, detailing the persons with dependent disabilities who were receiving assistance from a co-resident parent, was obtained by Carers coalition members and published in our COAG Submission (Nov 2005). These are all telling statistics:

Fig 6. ABS Customised Data for Australian's with disabilities living with a co-resident parent - DAC Survey 2003.

Persons receiving assistance from a Co-resident parent, by age of person	Profound Core Activity Restriction	Severe Core Activity Restriction	Total Profound and Severe	Total with a reported disability
0-15 year	74,400	77,200	151,600	198,800
16-29 years	20,400	33,200	53,600	112,000
30 years and over	22,400	33,200	55,600	80,400
Total 0-30+	**117,200**	**143,600**	**260,800**	**375,200**

These national co-resident parent carer estimates, tell us that around 55,600 persons with a severe or profound disability were aged over 30 years in 2003 (now over 33 years) and are living with co-resident caring parents who provide assistance to them. Many of these parents are already aged in their 70's, 80's and 90's.

Clearly, the human face of the statistics indicates that a disaster of enormous proportions is just waiting to happen as aged parent Carers die; leaving severely and profoundly disabled adults to the mercy of a crisis care system that has thus far failed almost all of them.

There are a multitude of reports and statistics to draw upon in assessing the contributions of caring families to the welfare of people with dependent disabilities. All of them are to a degree subjective in their estimates of who gets what and how much is it worth. If we are prepared to discuss the replacement value of the contributions of caring families to the supported accommodation needs of persons with a dependent disability, then a vastly different picture emerges over the debate on how much is enough in spending to support disabled persons who are dependent on another for their daily lives.

Putting these contributions into context is a simple exercise of multiplying the number of persons recognised by the CSTDA minimum dataset as 'potential population' for support services i.e. **687,710 persons**, by the average cost of a group home accommodation service of **$83,098.** (AIHW CSTDA Minimum Dataset 2003-2004)

Fig 7. **Potential population – cost of Group Home accommodation alternative**

Potential population / CSTDA service	Group Home - $ Cost per bed	Annual potential cost $
687,710	83,098	57.14billion

We can assume that some of the persons in the potential population; might be supported in a less costly living option. When considering the enormous cost of the current Disability services system it is immediately apparent that a radical new way of delivering a more cost effective and more acceptable diversity is long overdue.

The average cost of an institution/Hostel bed @ $74,461, a group home bed @ $83,098 and a community support package @ $18,883 multiplied by the potential population, the savings would be likely to be:

Fig 8. **Potential population – cost of Group Home accommodation alternative**

Potential population / CSTDA service	Average cost Institution/Hostel/ Group Home/ Community Package - $ per bed	Annual potential cost $
687,710	58,814	40.44billion

Eliminate all children 0-17 years with a severe or profound disability from the potential population of 687,710 for CSTDA services and you eliminate 15,817 children or 2.3% of the total. Thus, the potential population of adults aged 18-64 years becomes 671,893 persons with a severe or profound disability for whom parents and other relatives have no legal obligation to provide an accommodation and care service, save that a proportion may be in a legal/ married relationship.

In order to arrive at a place where the Senate Community Affairs Committee and the public will appreciate the full extent of the cost savings provided by co-resident parent Carers we need only look at the potential population of those aged 16-64 years and living with parents as defined by customised data from the ABS, 2003 Disability Ageing and Carers Survey.

Fig 9. CSTDA Potential population and persons living with a co-resident parent in 2003.

Potential population Aged 16-64 years lives with parent/s	Ave Group Home $ per bed	Annual potential cost $
111, 200	83,098	9.24 billion
Potential population-all ages 0-64 and living with parent/s		
260,800	83,098	21.6 billion
Potential population 30+ years and living with parents		
55,600	83,098	4.62 billion

When considering unmet need for disability supported accommodation services, governments must take into account the extremely large cohort of persons with a severe or profound disability aged over 30 years in 2003 as a critical mass of **55,600 persons** who have an urgent need for out-of-home or intensive in-home supported accommodation funding. **This group form the basis for urgent and immediate reform of the failed CSTDA funding system.**

ACCOUNTABILITY & TRANSPARENCY IN FUNDING & OPERATION OF THE CSTDA

Limited resources and relative need: two inhibiting drivers

The legislative base of the CSTDA and the Federal Disability Services Act 1986 inhibits the building of an effective and efficient system for the provision of specialist disability services (DSA 1986). Section 3A(2) of the DSA 1986 explicitly addresses limited resources for disability services and relative need: *In construing the objects and in administering this Act, due regard must be had to (a) the limited resources available to provide services and programs under this Act; and (b) the need to consider equity and merit in accessing those resources.*

This legislation enables the door to be closed on problems in the provision of specialist disability services for those who need them. “We have reached our financial capacity” is another way of putting it. More basically, people are told, “There’s no money.” There would be unbelievable outrage if, say, only 25 per cent of the people who met the criteria for the age pension were paid a pension and the other 75 per cent were told, “Sorry, there’s limited resources, and people worse off than you.”

While resources, i.e. tax dollars, are not unlimited, it must be recognised that the allocation to disability services from the global budgets of governments is a deliberate decision by each government. Herein lays the horror of Australia’s disability services: clearly, there is no intention to provide for universal access to disability services, even for the limited “target groups" of people coming within the scope of legislation and the Agreement.

What we have is time, energy and resources directed towards demand management, i.e. rationing, of services. It is difficult to imagine what could be more counter-productive, stifling, static and de-humanising for people with disabilities and their families. We also have the burdens and costs of care being borne by families, to the extent that disability is a life sentence, a noose around the necks of parents.

Whether or not “limited resources” and “relative need” should be the drivers of the provision of specialist disability services is a discussion which needs to take place as part of inquiring into the funding and operation of the CSTDA.

THE DIFFICULTY OF INFORMED DISCUSSION ON THE CSTDA

To be informed about the CSTDA is a very onerous task. As well as accessing the multi-lateral agreement and any bi-lateral agreements, a person must access a minimum of three reports:

1. the Australian Institute of Health and Welfare (AIHW) report compiled on an annual basis for the CSTDA national minimum data set;
2. the annual report of the National Disability Administrators;
3. the annual report on the review of Commonwealth/State service provision from the Productivity Commission.

The most recent reports are:

- Australian Institute of Health and Welfare (AIHW) 2005. Disability support services 2003–04: national data on services provided under the Commonwealth State/Territory Disability Agreement. AIHW cat. no. DIS 40. Canberra: AIHW (Disability Series). Published August 2005
- National Disability Administrators, 2005. Commonwealth State / Territory Disability Agreement Annual Public Report 2003-04. Commissioned by the National Disability Administrators. Prepared by Australian Healthcare Associates Pty Ltd. Australian Government Department of Family and Community Services.
  Published August 2005
- Productivity Commission Steering Committee for the Review of Commonwealth/State Service Provision (SCRCSSP) 2006. Report on government services 2006. Canberra: AusInfo. Published February 2006.

There are problems associated with the timeliness of these reports. The AIHW and NDA were not published until some 12 months after the closing of the financial year which they report on and some 24 months later remain the most current information on the CSTDA. The Productivity Commission report on the 03-04 data was not published until February 2006, because of its dependency on the AIHW data. As things are now, with the re-negotiation of the Agreement being considered, decisions as to what will happen as of 1 July 2007 are based on data which is reflects the state of play as three years previously.

In the meantime, we have governments making budgetary decisions and allocations for the provision of disability services, which have a relationship to the CSTDA, but are effectively another set of expenditure and service provision.

The accountability and transparency around the CSTDA would be greatly improved if government were required to present annual budget estimates for the service groups, and these were published with timeliness.

The Productivity Commission report (page 13.12) provides insight into complicating factors regarding financials:

> *Expenditure data were provided by Australian, State and Territory governments. These expenditure data might differ from information reported elsewhere (such as in departmental annual reports) because the financial counting rules and definitions used to calculate expenditure may differ.*

And as well:

> *Data in this Report may also differ from information reported elsewhere because the data here exclude users of specialist psychiatric disability services.*

This report (page 13.12) also provides insight into other difficulties:

> *The implementation of the CSTDA NMDS has led to some data quality issues. In particular, the proportion of service users and service outlets that provided data (response rates) and the 'not stated' rates of particular data items vary across jurisdictions.*

However, we have the National Disability Administrators (page 4) saying:

> *2003-04 also marks the first year for which whole of year data about the people who use CSTDA-funded services and the services they use became available. … These data, in combination with full year financial information, enable this report to be used as a baseline for future, cross-year, comparisons.* *(*emphasis added)*

Yet on page 54 / the Disability Administrators report is saying:

> The tables and charts presented throughout this report provide a comparative picture of CSTDA-funded disability services across Australia. The following factors should be considered when interpreting this data:
>
> ▪ Not all service outlets provided data for the period or submitted useable data. The number of service users reported is, therefore, likely to be understated, which means that the average cost per service user is probably lower than that reported.
>
> ▪ The mix or combination of services provided varies among jurisdictions. For example, some jurisdictions opt to provide more in-depth, and hence, more costly services than others.
>
> ▪ There are variations amongst jurisdictions in the collection of data relating to specialist psychiatric services. For instance, data relating to NSW, SA, Tas, ACT and NT exclude those users who only receive these services, resulting in a proportionally lower number of total users for these jurisdictions.
>
> For these reasons, comparison of service costs and other variables between jurisdictions should be made with caution.

Still more caution is on page 57:

> *Not all service outlets provided data and the number of service users shown is therefore likely to be understated. Outlet participation rates varied between States / Territories, with NSW having the lowest rate. Given this variation, the data presented should be used with caution.*

It is more than ridiculous that some 12 years after the signing of the first Agreement – 1991 – there are a myriad of presentations of expenditure and output measures, yet so many gaps in data such that a meaningful picture about the provision of specialist disability services is somewhat impossible to ascertain.

EXPENDITURE PER CAPITA OF THE POTENTIAL POPULATION AND SERVICE USERS

There is another cautionary note with regard to the calculation of expenditure per capita of the potential population (page 59)

> *It is important to note that the calculated values do not represent expenditure per service user. The average expenditure for each service user was substantially greater than the amounts shown. The main purpose of the calculation is to allow comparison of CSTDA expenditure in each State and Territory. It should also be noted that many factors may cause expenditure per capita to vary between jurisdictions, including the profile of service delivery.*
> *States/Territories*

It is not unusual, however, to see the per capita figures trotted out without the cautionary note. There is something deeply ironic in having to resort to a figure which has no further meaning, it tells you only one thing, i.e., the expenditure per capita of the potential population.

The figures of Total estimated expenditure per service user, makes for an interesting comparison with the expenditure per capita of potential population:

Fig 10.

State Territory	$ per capita potential population other than employment	Ranking	$ per service user	Ranking
NSW	$3843	3rd	$36 964	2nd
Vic	$5114	1st	$20,951	6th
Qld	$2609	8th	$24,495	4th
WA	$3556	5th	$13,988	7th
SA	$3500	6th	$13,336	8th
Tas	$4608	2nd	$21,609	5th
ACT	$3821	4th	$53,056	1st
NT	$2614	7th	$26,051	3rd
Australia	$3,854		$23,173	

Sources: NDA 2005; Productivity Commission 2006, Table 13A.30

The Table 13A.30 in the Productivity commission report, has cautionary footnotes

- The service user data used to derive this indicator have quality issues so estimates of jurisdictional efficiency need to be interpreted with care.
- The number of NSW service users is underreported for 2002-03 and 2003-04 because of low response rates.
- Victorian 2003-04 service user data used to derive this indicator are reported to be significantly understated because errors in the 'date of last service received' and lower than expected response rates have led to under-counting of service users.
- Payroll tax data for Queensland include paid payroll tax and accrued payroll tax.
- Payroll tax data relates to NT Government service provision and does not include expenditure for program management and administration.

PEOPLE RECEIVING A CSTDA FUNDED SERVICE

Perhaps the most telling figure about the operation of the CSTDA comes from the consideration of how many people are receiving services funded under the CSTDA as a proportion of the potential population.

Fig 11.

	No users	Potential Population	Users as % of potential	Rank
NSW	26 846	229,182	11.7	5th
Vic	44,581	165,315	26.96	3rd
Qld	14,933	134,671	11	6th
WA	18,947	69,074	27.43	2nd
SA	14,989	52,114	28.76	1st
Tas	3,825	17,004	22.49	4th
ACT	920	11,248	8.18	8th
NT	940	8,986	10.46	7th
Australia	125,709	687,710	18.27	

Source: AIHW 2005, Table A1.5; Productivity Commission 2006 Table 13A.30

THE POTENTIAL POPULATION AND WHO NEEDS A SERVICE

Even if one gives a lot of weight to the argument, "Well, the potential population doesn't mean all these people need a service at any one time." The conservative nature of the potential population means – these figures are calculated based on national age- and sex-specific rates of severe/profound core activity limitation from the ABS Survey of Disability, Ageing and Carers. An Indigenous factor and labour force participation rates (for employment) are applied. It is easy to comprehend that the number of service users for State and Territory government administered programs is a perpetual worry.

Whether or not service users are having their needs fully met by the service/s, being used is another moot point. The extent to which a person's needs are being met by the funded service is a critical outcome factor, and consideration must be given to this measure becoming part of the evaluation of the effectiveness and efficiency of service provision.

It must also be kept in mind that people with mild and moderate activity limitations are accessing services, so service users are not all from the potential population of severe/profound activity limitation. Nationally, 51.1 per cent of users of accommodation support services in 2003-04 had a profound core activity limitation, 38.9 per cent had a severe core activity limitation and 10.0 per cent had moderate to no core activity limitations (refer Productivity Commission 2006, Figure 13.7.) Nationally, 11.8 per cent of users of employment services in 2003-04 had a profound core activity limitation, 51.7 per cent had a severe core activity limitation and 36.5 per cent had moderate to no core activity limitations (Productivity Commission 2006, figure 13.8).

If one assumes that 10 per cent of the $1638.46 million expenditure on accommodation support is going to people outside the target group, this is $163 million nationally. For employment, $301.28 million, 36.5 per cent is $110 million. Factors such as these cannot be ignored when considering unmet need.

JOINT FUNDING ARRANGEMENTS

The CSTDA is at best a pathetic failure, in that probably the thing which it does best is allow governments and bureaucrats to play the blame game, rather than confront and solve problems.

The Agreement is also a handy place for governments to toss in a bit of money, a bit like feeding scraps to the chooks. The unmet needs funding of 2000, the ageing parent carers respite funding of 2004, and now the funding for young people in nursing homes all demonstrate the "feed the chooks" mentality.

While it might be argued that these are all significant increases in funding relative to the annual recurrent funding, it can also be argued that these were scraps to plug gaping holes in the fabric of agreement, areas which had become politically embarrassing to governments.

PENSIONS AND ALLOWANCES AS A FACTOR IN COMMONWEALTH GOVERNMENT CONTRIBUTIONS TO DISABILITY SERVICES.

The inclusion in the Productivity Commission report of Commonwealth expenditure on pensions and allowances, as if this expenditure is an offset against the Commonwealth contribution to specialist disability services, is nonsense.

If this income support is going to be included in reporting on disability services, there must be discussion about the effectiveness and efficiency of the income support expenditure, and the outcomes. Particularly it should be kept in mind that for children and young people with disabilities, those under the age of 16, the only financial support is via the Carers Allowance (Child), around $50 a week.

Any evaluation of funding arrangements must take into consideration the resources available. The work of Rory Robertson, Macquarie Bank Interest-Rate Strategist Macquarie Debt Markets Division (Sydney) is particularly worthy of consideration, and for this reason extracts are reproduced below.

Federalism Watch 4 July 2006

Four facts missing from debate on Federal/State financial relations by Rory Robertson (mobile: 0414 703 471; desk: 02 8232 5128)
**Treasurer Costello last week put "the problem of federalism" at the very top of his list of five big problems in Australia that need to be fixed (see http://www.treasurer.gov.au/tsr/content/speeches/2006/012.asp).

Background and summary **Federalism of course refers to the relationship between Federal and State (and local) governments. Section 51 of the Constitution assigned responsibility to Canberra for defence, immigration, the payment of pensions and telecommunications, for starters, on a long list of several dozen functions that includes "Lighthouses, lightships, beacons and buoys"! et al.

**Over the century since Federation, Canberra gradually has expanded its responsibilities into the fields of health and education in particular, and most recently into industrial relations. Treasurer Costello sounds keen to expand further, into ports, electricity, gas, water and beyond, although his thinking seems more about shifting towards national regulations than any big expansion of Federal funding. For the latest detailed breakdown of Federal and State spending, see Table 31 on p. 40 of http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/4BDD2FDD7D5CACC3CA25713F0016FAC4/$File/55120_2004-05.pdf **Over the century since Federation, Canberra has become the main collector of Australian taxes - 82% of the total in 2004-05 according to ABS 5506.0 - while the States naturally do more spending than they do taxing. Thus fiscal federalism for decades has involved Canberra each year collecting something like 5-7% of GDP worth of tax revenue for the States and delivering it to them in the form of "tied" and "untied" transfers/grants/payments (see Column E, Table A). **These days, the first (stable) 4% of GDP worth of transfers to the States comes via the GST as untied grants. Canberra of course keeps a tight rein on *total* transfers to the States, by dictating each year the level of non-GST transfers, mainly Specific purpose (tied) payments. With the States dependent on Canberra for nearly half of their total revenue, their natural tendency is to claim they have been "short changed", while Canberra's natural tendency is to claim it has delivered the States a "windfall".

My recent foray into this topic - by accident via an assessment of the Federal Budget in May - uncovered at least four key facts missing from the current debate.

- First, the "massive revenue windfall" the States are said to have gained as a result of the shift to the GST actually is tiny in the general scheme of things: $1.2b in 2005-06, or 0.1% of GDP.
- Second, Canberra's "tax take" as a share of GDP is at multi-decade highs on several measures, in part reflecting its own massive revenue windfalls in recent years (see Tables A and B, and Chart 1). Indeed, the latest ABS data viewed alongside the history in Figure 3.2 above suggest Canberra's tax/GDP ratio is at an all-time high. The 2pp jump in tax/GDP over the past decade (Column F, Table A) has meant that Canberra's sizeable Budget surpluses (Column I) largely have been both painless and hard to avoid, even with income-tax cuts announced in the past four Budgets.
- Third, Canberra's earmarking of the GST as a "State tax" has not produced any profound shift in Federal/State funding arrangements. With total (net) transfers to the States *steady as a share of GDP*, it is yet to be revealed why Treasurer Costello reckons the post-2000 funding arrangements have delivered to the States "the largest financial free kick since the Second World War".
- Finally, Canberra sets immigration policy, as noted above, while the lower tiers of government bear most of the responsibility for managing and funding the extra demands for housing, hospitals, schools, police, roads, public transport, etc. Any immigration programme - big or small - will bring with it a range of benefits (for example, increased output and taxes) and costs (for example, increased congestion and spending). With Australian immigration in 2006 set to exceed 100,000 for a record eighth-straight year (twice the run of the late-1980s; see ABS 3101.0 and Table 64 in ABS 3105.0.65.001.), it should be easy to understand that State and local governments are struggling with more than just - as many suspect - a simple lack of competence.

Canberra's recent embarrassment of revenue riches

**More broadly, Canberra's overall revenue windfalls in recent years truly have been extraordinary (see Table B). Four Budget updates since December 2004, for example, have delivered upgrades to four-year-rolling-revenue projections worth $123b in total, an aggregate that dwarfs even the $96b worth of net Federal debt that accumulated over the 25 years to 1996.

**For 2005-06 alone, the upside surprises in revenues over the past 18 months have totalled $25b; that's around 2-1/2% of GDP, or some 20 times the States' so-called GST bonanza.
**So that's where Canberra's money is coming from: a series of unpredicted windfalls in recent and projected tax revenue! Canberra's extraordinary revenue bonanza has meant that its sizeable Budget surpluses have been both painless and hard to avoid, even with income-tax cuts announced in the past four Budgets.
**Indeed, Canberra's recent embarrassment of revenue riches is unique in the history of Australian fiscal policy. More than ever before, the main problem when framing the Federal Budget this year was not "where to find the money to pay for everything?" but "how to spend all the excess cash?", to reduce projected surpluses from 2-3% of GDP to an acceptable 1% of GDP (Column I).

One simple suggestion to improve quality of federalism debate
**Canberra's flawed Budget data matter in part because the debate about Federal and State finances and functions is so important. As the population ages, Federal/State financial pressures inevitably will intensify as revenues are stretched to cover extra spending on things like pensions and healthcare.
**In such circumstances, one question increasingly asked will be whether the relatively cash-strapped States should hand over their health responsibilities to Canberra or, conversely, whether relatively revenue-rich Canberra should hand over more cash to the States to fund health.
**It's hard to know how this debate on fiscal federalism will evolve, but it would have a better chance of identifying solutions if Canberra's published Budget aggregates provided a reliable guide to underlying fiscal trends. If Canberra is interested in rebuilding the credibility of its published Budget history, shifting to "Own revenue" and "Own spending" aggregates would be a good place to start. [End Robertson reproduction.]

FINDING A BETTER WAY
The significant readily identifiable shortcomings in the CSTDA must be rectified in any future arrangements; or of any future agreements; or any future provision of specialist disability services, as they are:

- detrimental to the lives of people with disabilities, their families and carers

and

- detrimental to any evaluation of an agreement or the provision of services.

THE ROLE OF CARING FAMILIES IN PLANNING - WE HAVE NO ADVOCACY

The National Carers Coalition produced a number of documents and information articles for distribution among the caring families who joined the Walk a Mile in My Shoes Campaign. Amongst these documents were family carers views on age based discrimination, the exploitation of families, the imposition of one-size-fits-all supported living choices for disabled people, and the call for population-based benchmark funding to be introduced to failing disability services. These discussion papers and position papers were then distributed to networks across the nation including to peak disability organizations and advocacy networks with a request that the information be passed on to families everywhere.

It is necessary for families to seek the assistance of funded advocacy peaks in offering information and discussion papers for our peers, because neither the Commonwealth directly nor the CSTDA funded disability advocacy system, funds any disability family advocacy for families caring for those aged less than 65 years. We were shocked to receive a letter from the Victorian Disability Advocacy Network (VDAN), informing us that they would not distribute our information because they did not agree with our views.

Why we asked; did the disability advocacy networks in Victoria and NSW in particular and across the nation generally, expressed their collective objections to the fact that families caring for 93% of severely and profoundly dependent disabled persons wanted to have their say about unmet need? Disability Advocate bodies in particular, object to our views on ‘discrimination in living choices’ and accused us of wanting to have “institutions” back again. They object to us asking ‘why it is possible for nursing homes, hostels, village living, cluster apartments, etc to be accepted and in widespread use by the aged population of disabled persons but not OK for disabled persons under 65 years old?’

VDAN wrote to us:-
“While we share the “Walk a Mile” campaign’s aim to obtain more resources and support for people with disabilities and their families, we have strong concerns about some of the positions your campaign presents. In particular, VDAN rejects the assertion that deinstitutionalisation was just a fad of the 1970’s (not something we said) and that congregate models should be a legitimate option for future housing and support for some people with disabilities. While there is a need for greater discussion about models of housing and support that match people with different support needs at different times of their lives, there is too, much evidence against a return to large scale congregate care. (not something, we asked for)- Many people with disabilities can attest to the abuses and neglect that were associated with the institutional settings”........ and

VDAN continued:
"Given the concerns about the position you have put out in your materials, we will not be distributing your campaign materials or supporting your campaign. However, we would be happy to meet with you and your committee to discuss these concerns further and will work with and through VDAN to develop a collaborative approach."

Our offer to meet with representatives of VDAN, and our invitation for them to attend a region-wide forum in Victoria - were both ignored. The Disability Advocacy Network in NSW has followed a similar line:

A group calling itself, Family Advocacy- Institute for Family Advocacy & Leadership Development Assoc. Inc, is on a collision course with families over their stance on what is acceptable supported accommodation for people with disabilities in NSW. This group put into general circulation a group of Flyers condemning families for asking that all supported accommodation choices be available to people with dependent disabilities, in the state Minister's Round-table shake-up of disability services in NSW. Families hit back at this group, to argue that choice must include all options available to others, including high level nursing care, hostels, clusters, village living, etc...

In a response to families, this group calling themselves **Family Advocacy** included a 'mission statement' as follows:-
'Family Advocacy's mission is: "to attain positive social roles for people who have a developmental disability through the development and support of advocacy by families and by strengthening the knowledge, role and influence of the family." Their letter continues.....
'The organisation advocates on behalf of the interests of people with developmental disability through the actions of families." " **The organisation does not advocate on behalf of the interests of families.'**

The paradox of disability advocacy that does not advocate for families (without whom, hundreds of thousands of dependently disabled persons would be without a roof over their heads) is in deed perplexing. No good will come of this!

The advent of Carer Associations funded by the Commonwealth department of Health and Ageing is yet another paradox to be debated. These Associations claim to represent all unpaid family Carers, but clearly, they do not........ The NCC received this communiqué from a NSW family carer just this very week and it says;

" I felt I had to write this to say thanks for supporting the right of carers to have their say. I was at a forum in NSW Parliament House on Mental Health hosted by the Democrats for carers and advocates. A woman from your group stood up and told us that the senate were holding an inquiry into the CSTDA and were calling for submissions. She was encouraging carers to write to the inquiry telling their stories.

A representative from Carers NSW said that there was no need; Carers NSW would be writing one on our behalf. I was so shocked, I thought if this is what these large funded advocacy bodies do, encourage our silence, where was the hope? Are they funded to keep us mute, to keep us uninvolved in our own futures? I would have thought that their job was to widely distribute this kind of information, to encourage us to be actively involved in articulating our need for change.

What if I do not agree with their point of view? If a body is funded to assist us, wouldn't it do better to involve us? I thought it was more than a little off.
As an exercise, I decided to check out Australian carers websites to see if they were informing carers of the inquiry. I could find no reference to it on the 3 websites that I searched. Carers Australia, Carers NSW and Carers Victoria. I am at a loss to understand this. I looked on your website and there it was as a link to the senate site. Thanks for the great work you are doing in trying to get the message out to care to encourage us to have our say. MM"

Unpaid family Carers of persons with disabilities therefore must insist; that any government reform of disability services under the CSTDA is inclusive of the urgent need for funding of disability family advocacy at the national, state and regional level, as a matter of justice.

Quite clearly we are **not represented by the disability advocacy sector** nor, it would seem are we represented by the aged care funded, CARERS ORGANISATIONS who feel they can speak for us without giving us any say - Mushrooms all, we **therefore have no funded voice to government save that, which we generate ourselves-**

THE DISABILITY SERVICES INDUSTRY VOICE - AND FAMILY CARERS

To discuss the reform of disability services provided under the CSTDA -MDS is to discuss an industry that delivers an accommodation support service to 4.8% of the potential population and a community services to no more than 11.4% of the potential population.

The critical question is raised again here, of just why it is then, that the Industry peaks and the disability advocacy peaks have so much influence over policy and planning decisions whilst families who provide accommodation and care to 93% of dependently disabled persons are ignored altogether.

Caring disability families are treated like mushrooms, kept in the dark and fed on fertilizer. This is a recipe for an end to unpaid family caring into the 21century, unless urgent action is taken to remedy the situation. We have found our own voice and we are screaming hear us roar!

WORKCOVER – AND CARERS - THE FAMILY HOME IS NOW A WORKPLACE

The deliberate policies of Government that encourage family-based provision of support to persons with dependent disabilities of all ages has created a minefield for caring families. In order that family-based care is sustained at the highest possible level, governments have concentrated their funding efforts upon in-home support service systems such as domestic work, personal care and respite services.

The industry that provides these services has a life of its own, managed by regulations such as Occupational Health and Safety and Workcover for paid employees. What is becoming more and more apparent is that this industry of ‘paid help in the home’ is not only an ever increasing encroachment upon the privacy of the family home, but it has now declared the family home to be a “workplace.”

This declared workplace is now a place in which families are being sued as “third party liable” under workcover regulations in some if not all states. Laws which protect paid care workers but give ‘NO PROTECTION’ to the caring family are an abomination that will see more and more families think twice before having any in-home help for which they can be potentially sued.

Fundamental argument put forward by the supporters of this bizarre escalation of risk to caring families is that the workcover agencies of government maintain that a families home and contents insurance policy will cover them against such a liability. This is a bold assumption which will exclude the vast majority of caring families who are renting and therefore have no home insurance. Furthermore, it is presumptuous to assume that those who do have a mortgage or a home can be held liable whether insured or not because some arm of government has decided the family home is now a workplace.

At least one state (Victoria) has exposed families to Law Suite for third party recovery of a paid workers compensation costs. This government totally refused to countenance exempting caring families from third party liability for paid care workers, even though they had previously passed legislation exempting volunteers working for funded agencies.

We are aware that Queensland has similar workcover legislation and that Queensland Services have introduced similar occupational health and safety (OHS) limitations upon families receiving in-home support.

The critical issues for the Commonwealth to consider in this matter are based in the fact that they have assumed responsibility for Industrial Relations Law across the nation. It therefore behooves the Commonwealth to also assume responsibility for workcover and OHS to ensure that family homes **are not turned into a paid care-workers workplace.**

Unpaid caring families must be protected from any workcover liability for any paid care-worker assisting in the family home. This issue alone is likely to dissuade countless families from having in-home assistance to care and therefore a refusal to care when the burden is too great to bare. This is an example of what families now face:-

> "Last week I was informed by phone that the City Council HACC service would no longer provide my 14yr old son with personal care based on his size (14 year old profoundly disabled -weighing 40 KG). They said they would have to do an occupational health and safety (ohs) assessment (again) before putting the care back in, but they must have been aware of the implications for me and my family by doing this.
> If I was to hurt myself, struggling with two children with profound disabilities where would they go? Into accommodation that doesn't EXIST.
> The Service Provider cant just cut out care when proper equipment is provided, based on complaints that the carers have tired backs after working with my boys for one hour, 2-3 times a week, sometimes less. The service provider says they have a duty of care to the carers, what about the duty of care to me and my boys.
> I have covered some of the care with a more reliable agency and am struggling to cover the rest on my own.
> Lisa .....Parent/slave"

HOW DO WE SOLVE THE PROBLEMS ENDEMIC IN THE CSTDA

For all the citizens of Australia to be afforded their full citizenship rights as espoused in Section 117 of the Commonwealth Constitution, there is little doubt that urgent reform of disability services is mandatory.
We urge the Commonwealth to:-

(a) Stop age discrimination in the provision of disability support services to Australian citizens and ensure equal access to supported accommodation and community support services are provided for people of all ages who have a dependent disability.

(b) Stop the blame game between the states and territories and the Commonwealth and take full responsibility for the provision of accommodation and support services for all citizens with a dependent disabilities.

(c) Take immediate steps to introduce new legislation that will give persons with dependent disabilities the same choices in living options as are available to the rest of our citizens including the frail aged.

THE COMMONWEALTH AGED CARE SYSTEM - COMPARISON

Many arguments that are used by bureaucracies and politicians alike in the debate over what is acceptable as a living option for disabled people are contradictory, discriminatory and without substance. We need look no further that the aged care system of accommodation and support services for elderly citizens to discover this.

When Sauce for the Goose must be Sauce for the Gander
The division of powers under the CTSDA and Aged Care banners is at the heart of 'age' discrimination which divides our citizens with dependent disabilities based upon an arbitrary age delineation of over 65 years equals Aged Care and under 65 years equals Disability services.

Australian's aged over 65 years who have a dependent disability have access to aged care services in every major town and city throughout the nation. These services include housing and supported accommodation options such as nursing homes, hostels, village living, cluster apartments, blocks of flats and purpose built units.

States governments sanction none of these options for people with disabilities and this is clearly AGE DISCRIMINATION. ... Caring families demand to know why this issue is swept under the carpet by governments, bureaucrats, disability advocacy and the community at large.

Furthermore; the 'age' and 'jurisdictional' divide creates an extremely unbalanced system of funding and policy directions that have led to restricted choices and massive under-funding of the disability sector and allowed governments to blame each other for this failure.

If the states are **correct** in their policy objectives to ban all living options choices for people with dependent disabilities aged less than 65 years, then the Commonwealth governments aged care policy **is wrong** and all aged care facilities, **must be closed, along with all condemned disability 'institutions**.'

Policies that coerce families to care for relatives with dependent disabilities until death, must be imposed upon "all families" not just the families of the disabled aged under 65. Unless and until all family caregivers are treated as equally valued contributors to the welfare of disabled Australians, the system **will remain guilty** of GROSS AGED DISCRIMINATION.

The anti-institutional lobby accepts the common parlance that "Institution" means something 'Bad" because of their own experience with the "Institutionalisation" of a few thousand people with disabilities in congregate care settings throughout Australia's dark past. It's funny how 3 decades on from de-institutionalisation, so few people have been moved out in spite of all the rhetoric.

Institution does not by definition mean "institutionalisation" which only occurs when people are subjected to a "mundane" "Repetitive" and "Mind-Numbing" existence; all of which, categories can be applied to a 5/6 bed Group Home or indeed the family home where people with disabilities are housed inappropriately with frail aged parent Carers.

What makes a dwelling an institution is not the size of the roof, but the quality of the service, the supervision that is applied and the checks and balances enforced.

The commonwealth clearly understands this because no-one ever refers to aged care nursing homes and hostels as "institutions" and national aged care policy only ever refers to its services as 'supported accommodation' or 'residential services' regardless of the fact that many facilities have hundreds of beds under the one roof.

So do let us get our terminology right and put a stop to the 'bureaucratic lame excuse for doing nothing' for the vast majority who have **NEVER SEEN THE INSIDE OF AN INSTITUTION, LET ALONE LIVED IN ONE.**

Conclusion:

The ignored reality of the anti-institutional lobby is that families and friends have always cared for over 93% of all persons with a profound or severe dependent disability at home. The ignored reality is also that decades of neglect has left us with a rapidly ageing population of parent Carers who will die and their sons and daughters will then be homeless. Why?

Because the **“in-home only”** lobby has mightily **‘dumbed down’** the reality that “NO-ONE ELSE” in our society is expected to provide a “WHOLE OF LIFE - CARE SERVICE” for a child, adult child or any other relative, we are stuck in this time warp of indifference and neglect.

The CSTDA is reaching the end of its five year reign on the 30th June 2007. This must be the last such Agreement between the Commonwealth and the states and territories.

There must be an end to ‘age discrimination’ upon persons with disabilities aged less than 65 years.

There must be an end to ‘discrimination’ against families shouldering the burden of accommodating and caring for the dependently disabled citizens of our nation without due obligation being paid.

There must be an end to excluding caring families from the benefits of paid work, wealth, health and prosperity enjoyed by their non-caring peers and an end to unpaid care slave labour.

It is true to say that, the worth of a nation will be measured by how it treats its citizens. No-one will remember the economic rationalists with warmth. Few will recall who was on top of the list of the wealthiest Australians. Many will remember how disabled citizens are placed on the lowest rung of the priority ladder.

The 2.6 million unpaid family Carers of this nation who are responsible for a huge chunk of the budget surplus of the Commonwealth are waiting for the mutual obligation they are owed for caring for the least of these our brethren.

The National Carers Coalition is fully expecting the Senate Community Affairs Committee to hear our cry for justice for people with dependent disabilities aged less than 65 years. We fully expect you will ensure that the CSTDA is not renewed because the Commonwealth has accepted its responsibility for all Australian citizens.

23. Recommendations

1. Treat all citizens with dependent disabilities equally and stop the blame game between commonwealth and states by having the Commonwealth assume full responsibility for services to persons of all ages who have a dependent disability.

2. Remove all aged based discrimination from accommodation and care support services both out of home and home based.

3. Introduce population based benchmark funding to disability services as an urgent priority.

4. Provide funding for disability family advocacy as a matter of urgent priority, which matches the level of funding provided to disabled persons themselves at the regional; state and National level. Ensure that all decision-makers hear the voice of caring families. Ensure family Carers owns this new organization by establishing it from the grass roots up.

5. Take immediate steps to assist frail aged parent Carers to cope with the burden of care that is destroying their health and speed up the transition of their adult sons and daughters to age appropriate supported living arrangements of their own choices.

6. Provide families caring for disabled persons with the same level of in-home and out-of-home assistance as that provided to Carers of the aged.

7. Introduce national Carer Recognition Policies and protect caring families from Workcover liability where paid help is provided in the family home. The family home is not a workplace.

8. Ensure all full-time caring families have access to at least four weeks of respite care every year as a right not a privilege. This includes the necessity to build dedicated respite care facilities for those with severe and profound dependent disabilities and living with families.

9. Stop the poverty trap for caring families and legislate solutions that give primary caregivers access to paid work.

10. Meet your mutual Obligations to the primary Carers who contribute so much to the nation and receive almost nothing in return.

Hear the voice of the families who are the life blood of disability accommodation and personal care service provision throughout the nation. Stop age, choice and access discrimination for those for whom we care. Remove the barriers to a normal life for all of us.

Attachments: *NCC - COAG Submission November 2005*