

# Who is listening to us?

## Families caring for people with disabilities have NO Voice

The absence of any funding of **disability family support and advocacy** is clear evidence of the neglect of successive governments that is so obviously manifest in the current failed CSTDA negotiations and the burgeoning issue of unmet needs for specialist disability services.

Families provide over 92% of all the accommodation and personal care services for people with dependent disabilities throughout the nation, yet they are denied a place at the planning and policy table at either state or federal level. The decisions that most affect families who freely contribute \$multi-billion to the national economy are made without representation from families. Governments' court and listen to funded disability sector peaks and the funded disability advocacy peaks and continue to leave families out in the cold by design.

Families need to ask themselves, why it is that Disability person Advocacy is funded at the national state and regional level, but disability family advocacy is not?

Why does the Commonwealth aged care Department fund Carer Association's whose charter is predominately aged care, but the federal government still refuses to fund a similar National Disability Family Voice for families caring for citizens aged less than 65 years old?

The then incumbent minister, shelved the National Family Carers Voice, whose final report clearly demanded nothing less than that which persons with disabilities themselves enjoy, for families of the disabled, and the 'why' remains unanswered today.

There are 71 disability advocacy organisations, who currently enjoy taxpayer funding via the CSTDA. The Disability Advocacy Review Final Report (1999) recommended that disability family advocacy be funded, but deaf ears refuse to heed the call. This strategy by governments is a deliberate 'silencing of dissent' by caring families. We do not have to accept this 'discrimination' and gross injustice.

Most recently, the Senate Inquiry into the funding and operations of the Commonwealth, State and Territory Disability Agreement (CSTDA) Final Report found that families were discriminated against and recommended that family advocacy be funded by the CSTDA. Yet the Federal Minister still refuses to consider such a proposal.

1 million Victorians have a disability and at least half of these depend on support from a family member or friend for their daily life. Contrary to popular belief, the vast majority of persons with a severe or profound disability have always relied upon family and friends for their daily accommodation and care. The myths perpetuated by the government to hide or water down all the unmet needs people have for such support are by now legend.

The illegitimate use of the word "institution" to stop all claims for new supported accommodation models and facility based respite care is a classic example of a strategy of 'silencing the lambs.' The deliberate restriction of 'choices' in the provision of disability accommodation and the current separation of accommodation from support services in Victoria, is another mechanism for quelling demand that must be exposed for what it is.

**All of these strategies are designed to coerce families into continuing their unpaid accommodation and care role no matter what the personal cost.**

Government is not alone in this endeavour, for they have skilfully lassoed **disability advocacy and disability peaks** with a '**30 pieces of silver strategy**' that has disability advocacy blinkered into thinking they have all the answers, when clearly the statistics prove this is an absolute fantasy.

The bottom line is that over 706,600 Australians aged less than 65 years have a severe or profound disability. Over 55,600 of these people with a severe or profound disability are over 34 years old and still living with a co-resident parent carer who provides assistance to them. (ABS Disability ageing and Carers survey 2003).

In 2004-05, the Commonwealth state and Territory, Disability Agreement (CSTDA) minimum data set of the people who have a service compared to those who have none tells the true story. The dataset comparisons are based upon people with a severe or profound disability, the '**potential population**' who may require government funded services.

*Only 33,787 persons received any form of funded accommodation support in 2004-2005, with just 15,792 having a government funded bed. This means that over 672,800 people with a severe or profound disability did not have any funded accommodation support at all.*

In 2004-2005, just over 10,700 Australian people had a group home bed and just over 5,000 a larger scale supported accommodation service. This means that less than 4.8% of the potential population for disability housing services actually have one. *This also means that over 93% of all people with a severe and profound dependent disability relied upon family and friends for accommodation and support in their everyday lives.*

**It is this reality that the governments take great steps to hide! Without families providing 'whole of life support' to sons, daughters, siblings and other kin the cost born by taxpayers would be monumental.**

The national disability is currently **\$3.6billion recurrent, but the reality is that \$10.9billion recurrent** is required to meet a population benchmark of just 18 places/packages of support per 1000 of the population aged 15-64 years. This would only address the unmet needs of 1.8% of the population or half the estimated number of persons with a severe or profound disability found in this age group (3.9%).

**Conservative national estimates of unpaid care value are put at \$30.2billion a year and delivered by 2.6million caring families.**

**The cost is now a burden almost entirely weighted upon the caring family and that is so wrong. A balance must be struck before the burden causes unpaid care to collapse.**

There is a better way, age discrimination must cease and funding of disability services must have parity with the funding levels provided in aged care. Aged care services have used a benchmark funding formula for years. The benchmark in aged care is 108 beds or packages /1000 of the population aged 70+ years.

Government is not going to make these changes happen for families unless we as a nation demand them because they cost money, a lot of money. We believe that the reason why it will cost a lot of money is two-fold;

1. Governments have grossly neglected the sector for decades by deliberate design in order to avoid their duty of care to disabled citizens; and
2. The one-size-fits-all mentality restricting choices in accommodation options has blown costs out of any possible reality for mass housing inclusion.

United caring families say we will not tolerate the crumbs off the budget table. We have a right to sit at the feast along with the rest of our society. Our collective contributions to the welfare of the nation are so huge that government is not willing to speak it 'out loud.'

**2.6 million caring families have the ability to change the face of politics in our state and our nation. The potential with just two votes per family is over 5,000,000 votes. Many marginal seats are now at risk.**

Disability families have the power to create chaos if they choose not to care any more. The future of full time care is at extreme risk from neglect and abuse.

Governments should not be making plans to provide assistance to aged parent Carers; governments must be making plans to eliminate the need for ageing parents to be caring at all.

*Parents of profoundly disabled sons and daughters are the only families unable to have an empty nest, because society has closed its collective eyes to the problem. No retirement planning, no superannuation, no pay, no sick leave, no annual leave and no compensation; this is our lot in life.*

The National Carers Coalition (NCC) formed as a result of the Walk a Mile in My Shoes Campaign, is a welcome extension of the principle of a better way that invites caring families across the nation to take a stand with us and to demand justice and a better deal.

We aim to mount a federal campaign demanding a fairer deal. There is a way. The Commonwealth must stop age discrimination and give caring families and people with disabilities back their citizenship rights:

The Senate heard our cries for an Inquiry into the failings of the CSTDA and the Community Affairs Committee review found that **"the caring burden on families was crushing and unreasonable"** and recommended that 'substantial new funding be made available by governments for the 4<sup>th</sup> CSTDA due to commence July 2007.'" [http://www.aph.gov.au/senate/committee/clac\\_ctte/cstda/submissions/sublist.htm](http://www.aph.gov.au/senate/committee/clac_ctte/cstda/submissions/sublist.htm)

This Agreement now lays in limbo because the states and the Commonwealth cannot agree on a level of funding increase to deal with unmet accommodation and respite needs.

Caring families are demanding the introduction of Population based benchmark funding to give disability services parity with aged care funding. This is the only way justice will be served for all citizens who have a dependent disability. We have proposed a formula by which this can be achieved and we are happy to share it with anyone willing to listen.

**We now challenge all politicians to include benchmark funding in their disability policies. Our recommendations for Federal / State Policy change include:**

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 introducing a new funding formula for services to persons of all ages who have a dependent disability.
2. Introduce population based benchmark funding to disability services as an urgent priority and remove all aged based discrimination from accommodation and care support services both out of home and home based.
3. As a matter of urgent priority: Provide funding for disability family advocacy, which matches the level of funding provided to disabled persons themselves at the regional; state and National level to 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.
4. 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 choice.

5. 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.
6. 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.
7. Stop the poverty trap for caring families and legislate solutions that give primary caregivers access to paid work.
8. Meet mutual Obligations to the primary Carers who contribute so much to the nation and receive almost nothing in return by legislating 'rights' for family carers.

*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 all barriers to a normal life for Carers.*

*Caring families are indispensable, caring families must take back control of their lives by saying NO to exploitation as unpaid slave labour. Take a stand with us and change the world for our most vulnerable citizens. Say No to politicians who will not give Carers and people with dependent disabilities a fair deal.*

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