

## **Without reprieve**

By **Jean Tops** - posted Monday, 17 September 2007 –

What kind of a nation are we, when we close our eyes to the appalling government neglect of providing care and support to our most vulnerable citizens. Critical among the forgotten, are people with severe or profound disabilities and the families who provide more than 92 per cent of all their accommodation and personal care needs.

In the lead up to the coming federal election it is time to ask, "Who among us cares that the dominant political parties have no disability or unpaid family carer policies at all?"

The scramble by high profile sectors of our society for a slice of the \$17 billion budget surplus is loud and organised, and overshadows the marginalised and oppressed. Politicians and other reformists ignore entirely the fact that a stand-off is raging between the states and territories (responsible for delivery of disability services) and the federal government, because neither can agree on increased funding for the growing list of un-met needs for disability services.

Across the nation, more than 2.6 million ordinary families struggle to balance family, work and caring!

Hardest hit among them are the families providing full time care for sons, daughters, partners and siblings, who by accident of birth, catastrophic event or illness, are reliant upon others for their daily living needs. The staggering truth is that there are 706,800 persons with a severe or profound disability aged less than 65 years in a struggle for existence, because governments at best provide an ad hoc system of care services and at worst deliberately neglect them.

The system of disability services is divided on age-based grounds, with aged care a federal responsibility and disability managed by the states under the Commonwealth, State and Territories Disability agreement (CSTDA). This five-year agreement regime commenced under Labor governments in 1992 as a means of stopping the overlap of services between jurisdictions.

Its chequered history has seen the "blame game" between states and federal government delay the signing of the CSTDA, a year past its use-by date on most occasions. The fourth of such agreements, due for signing by July 1, 2007, now languishes in a "stand-off" over who is responsible for funding increased services to meet the worsening accommodation crisis that now exists.

The current CSTDA provides, just 33,700 of the 706,800 people with a severe or profound disability with an accommodation support service: less than 5 per cent of the potential population. The system relies on an ad hoc state-by-state contribution of funds to which the commonwealth contributes about a further 20 per cent. This ungainly mix provided a national purse of \$3.6 billion in 2005-2006 and is the source of the squabble raging over unmet needs funding today.

By contrast the aged care system provides more than 204,000 beds and intensive support packages with a national budget of about \$8 billion, of which more than \$7 billion is directed solely by the federal government to the aged care accommodation and support system. Aged care is funded under a population-based benchmark model that now funds 108 beds/packages per 1,000 of the total population aged over 70. No such system exists in disability services and family carers are demanding to know why.

The myth 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 of "community inclusion" rhetoric and expose it for what it is: a contrived means for senior bureaucrats and government ministers to "opt out of responsibility" for our most vulnerable citizens.

"Community inclusion" is a euphemism for restricting the options available to people with disabilities in order to coerce families into maintaining their free care role.

Through their own statistics, the federal government acknowledges that caring families contribute in excess of \$32 billion a year to the national economic bottom line. All governments have a vested interest in offering poor quality services to people with disabilities: unpaid family-provided personal care and cost free accommodation services is a cash cow for government at all levels (a single group home bed costs taxpayers on average \$85,000 a year).

Australia is a signatory to the UN Convention on the Rights of People with disabilities. The preamble of which clearly states:

*... convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the state, and that persons with disabilities and their family members should receive the necessary protections and assistance to enable families to contribute to the full and equal enjoyment of the rights of people with disabilities ...*

Article 16 of the Convention says in part:

*... States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring inter alia, appropriate forms of gender - and age sensitive assistance and support for persons with disabilities their families and care-givers ...*

And again at Article 23.3:

*States Parties shall ensure that children with disabilities have equal rights with respect to family life, with a view to realising their rights, and to prevent concealment, abandonment, neglect and segregation.*

At the present time, there are some 55,600 people with severe or profound dependent disabilities, aged over 34 years, still living with ageing co-resident parent carers across our nation. These citizens, who are almost entirely reliant upon family, are indeed vulnerable, isolated and segregated from a society that refuses to provide them with the same or similar living choices as everyone else. Frail aged parents are still caring, long past the age when most adults make their own way in our society.

Governments claim that the needs and voice of parent-carers and families are represented by disability organisations, peak bodies and focus groups, but the truth is that many of these funded organisations have become an arm of government and actively oppose the rights of families to a voice in planning and services. They engage in activities that inform and reinforce an "ostrich" policy, sloganeering and rhetoric such as "home is good, everything else is bad", and brand facilities as "institutions" in a blanket denial of a person's "right to choose" from all living options available.

Many of these organisations in fact foster a mentality and objective to denigrate the valuable and important role that family carers play in society. Some are actively condemning the current federal government plan to provide 1,750 new disability accommodation beds in 175 purpose-built facilities within the next five years.

The government plan is aimed at easing the “crushing and unreasonable burden” on aged parent carers, and providing adult people with dependent disabilities with a home of their own. This response by the Federal Government is a departure from their present role in service delivery, and is a direct action taken in the face of the abject failure of the system administered by the states.

Some among these funded organisations claim the federal government is planning to “rebuild institutions” because of this proposal for 175 facilities for 1,750 persons equaling 10 bed units or clusters. These same unrepresentative groups are silent about the widespread aged care accommodation services with 30, 60 or even 100 beds, in every town and city across the nation, and which are never strangely referred to as “institutions”.

The proponents of such discrimination are the very same groups who condone the widespread practice of placing people with disabilities into privately managed, for profit, supported residential services of 20, 30 and 40 beds, where a subsistence room and meals service for younger persons with disabilities and mental illness is tolerated by eyes and voices silent and blinded by self interest.

These professional careerists have helped enshrine an “industry” that has built up egos and fortresses that cannot be breached by those they purport to represent and assist. It is quite astonishing when you look at the number of groups in the disability sector and realise that many openly oppose families having a voice at all.

Families of people with dependent disabilities are locked into providing the primary accommodation and personal care for their family member with a disability beyond an age when it is reasonable for them to be required to do so, because society allows it to happen.

Families are the “meat in the political sandwich” twixt well paid bureaucrats and those with vested interests who restrict people with dependent disabilities from making choices, while they “cream off the grossly inadequate funding pool” to make a very comfortable living for themselves. Such individuals conspire to refuse us a voice, and condemn families for seeking a fair deal for their loved ones.

By excluding families from being heard, the “system” has sentenced hundreds of thousands of caring families to isolation, poverty, discrimination, exploitation and abrogation of any rights. Governments have indeed sentenced more than 700,000 families, caring for profoundly disabled persons in the family home, to a death without reprieve.

By effectively forcing families to give up on caring for their children, through denial of adequate support, the government risks losing more than \$30 billion worth of unpaid accommodation and personal care services. Society will then wave goodbye to a \$17 billion federal budget surplus or any state surplus for decades to come!

*Jean Tops is a lifelong family carer for her 38-year-old daughter who is deaf, blind and profoundly dependent from the effect of the Rubella virus. Her two eldest sons were born with Phenylketonuria (a rare metabolic disorder of protein metabolism, which untreated, causes irreparable brain damage). A life time advocate for caring families, she is President and Founder of the Gippsland Carers Association and a founding member of the National Carers Coalition.*