

The Committee Secretary
Community Affairs Committee
Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Committee Members,

Re Inquiry into the funding and operation of the CSTDACSTD

As parents of a 32 year old profoundly physically and developmentally disabled son we welcome this inquiry and would like to hope the outcomes will improve the lives of the members of our family and give us some hope for a future.

Our son's physical condition is declining and he needs full assistance in all aspects of his life i.e. personal hygiene, mobility, eating, organizing finances, trying to provide some form of recreation etc. not to mention the time taken to fill out Govt. forms. This is a full time job in itself –unpaid of course- but, like everyone else we also have to earn money to eat and pay bills so between us we find time to work in paid employment. Eight months ago after one of us became temporarily disabled due to an accident we were in a crisis situation. Trying to access a broken down under-funded State System almost drove us over the edge and if it wasn't for some fellow carers in a similar situation to ourselves I hate to think where we would be now. *There is no system in Australia to turn to for assistance if you are the parent/cares of a disabled person in crisis.* You perpetually run into brick walls, counterproductive beaurocratic policies and inflexible services.

We as carers get very tired of hearing how much Government money (both Federal and State) is spent of Disability Services. It is obvious much of this money is *misspent* and does not reach those who need it.

As well as full on caring and working in paid employment we also have to find time to lobby politicians and advise them of our needs i.e. *supported accommodation, respite care, home assistance etc.etc.etc.* We are aware there are many Advocacy Groups are funded to advise Govt. of our needs but it is obvious that they are not aware of our needs and misrepresent us.

We know that things like a family holiday are totally out of the question for us, but one thing we dearly hope for in our lifetime is that we will see our disabled son happy in his own supported accommodation before we die. In our wealthy country this should be possible, particularly when Politicians have just been given an exorbitant allowance just for postage for junk mail.

Marilyn and Richard Jones, carers of Robbie Jones.