

## Submission No. 756

(Inq into better support for carers)

Committee Secretary  
 Standing Committee on Family, community, housing and Youth  
 PO Box 6021  
 House of Representatives  
 Parliament House  
 CANBERRA Act 2600  
 AUSTRALIA

27/6/08

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

*The views I give are based on caring for an intellectually handicapped 24 year old who needs 24/7 care. I will make brief statements about our family situation which are relevant to the submission comments that follow.*

**The role and contribution of carers in society and how this should be recognised:**

**Role:** to care, support and protect an individual who cannot function physically, emotionally and cognitively in society and also to provide a safe and harmonious working environment for those who assist our family to achieve this goal.

**Contribution:**

- We are unpaid 'employees' (not always by choice) of the government and therefore save Australia a lot of money.
- We provide others with low income employment.
- We provide a loving and safe environment for a disabled person

**Recognition:** As it stands today, we should be recognised as a sector of society that the Australian Government does not value and has forgotten. We stand behind, or perhaps have replaced 'The Stolen Generation.' For a government to 'stand tall' on human rights policies it should first ensure that ALL of its citizens have equal rights and opportunities to pursue financial and emotional stability.

**The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.**

*Prior to our daughter leaving school in 2003 we were a happy family unit being able to both work and, to a degree, socialise with our daughter. Post school, our lives were to dramatically change. Unbeknown to us at the time, the 'Australian Way' no longer demonstrated a duty of care to intellectually disabled individuals once they left school. The PSO funding allocated to my daughter was insufficient, allowing for only 5 hours a week one on one support. My pleas for more were met with 'she doesn't meet the criteria', followed by 'sheltered workshop will suit'. Not to be. She declined quickly over the first year resulting in an emotional breakdown simply because she couldn't cope without one on one help. More pleas for funding, met with 'she doesn't meet the criteria' 'go to mental health for help'. Feeling isolated, and desperate, we did. Medication followed, side effects emerged which accelerated her decline. More pleas for funding, same 'criteria mantra', of course her decline continued as did ours. She ended up being flown to RPH where she spent 2 months in the stroke unit in a Catatonic Coma. She came home a stranger, one that resembles an 'ICE' user. She then became eligible for the extra support funding we kept asking for. A whole whopping 15 hours a week. That was in the year 2006. Today, she remains the same, a*

*stranger to us and chronically and seriously ill. In brief: 2003 (last year of school) our daughter was a happy, gentle, beautiful intellectually disabled individual, Post school 2008: since medication she has declined further intellectually, now suffers from Akathisia, anger and aggression, severe Obsessive Compulsive Disorder, Tardive Dyskinesias - Cervical Dystonia, oramandibular dystonia, Tardive dementia, Tourettism insomnia, Severe and chronic Panic and Anxiety Disorder. She has attacked 15 people in public places and has seizure like episodes. Perhaps someone in the Australian Government can justify to us why this was a necessary post school experience for my husband and me who cared for and loved our daughter unconditionally. The funding we asked for was for her needs only, and your sadly lacking' criteria' denied her the support she needed and has, as a consequence, destroyed her life and ours.*

**The following social/economic barriers now exist for us due to the above:**

- **Emotional decline.** a sense of hopelessness. Not wanting to go on. Husband keeps breaking down. Had to reduce hours at work for 2008 to cope with stress. Sleep deprivation.
- **Financial loss.** Cannot repay mortgage. Have to live off equity from our home. We were working towards being self funded retirees. Now will have to retire early in order to cope and so bear the brunt of unfair taxes on our superannuation.
- **Loss of employment.** 2003- my employment had to be reduced to part time. 2006 could no longer work as daughter needed 24/7 care. We receive the Maximum amount of PSO funding which amounts to 15 hours a week. Not enough to sustain meaningful employment as a teacher. Finding a job is not a problem, getting there is.
- **Social isolation.** Daughter cannot leave the house due to Panic Disorder/attacks on people. Of course, nobody comes to see us. Too stressful! Paid carers have to work from our home. We have lost our privacy as well. No social networking.
- **Marital issues:** We share no common time together. No holidays, no leisure time. We go out separately – one of has to stay home and look after our daughter.

**Finding and retaining employment**

- Employment is not an option because:
  - lack of carer funding and a lack of carers per se,
  - carers are poorly paid and often leave.
  - no relief carers available when regulars are unable to work.
  - of the emotional stress of caring
- To ensure equal opportunity and social justice for carers, meaningful and adequate funding must be put in place.

**Practical measures required to better support carers**

- **A review of funding criteria.** From our experience, this is sadly lacking in humanity and so threatens the wellbeing of the disabled individual and their carers. The carers should have a primary role in deciding the amount of funding that should be given to a disabled individual upon leaving school. (PSO funding)
  - Funding applications as they stand favour physical, neurological and genetic disorders. Any conditions pertaining to emotional/mental disorders which may accompany the aforementioned conditions in an individual are not recognised yet these behavioural conditions can have a devastating effect on the individuals and their carers. The funding criteria formulated by the Government, is discriminatory and lacks social justice for the disabled individual and their carers.

- Social equality. Carers who have looked after a disabled individual since birth should have the same rights to funding/respice/accommodation as carers of accident victims, the elderly etc.
- Accommodation funding should be available when it is evident that families can no longer sustain the caring role, instead of having to wait in a queue that never moves. By ignoring this worsening situation the Australian Government effectively harms the emotional wellbeing of the primary carers which can have devastating consequences, socially and financially.
- **Employed carers** should receive the same rate of payment as Education Support Assistants. The Duty of Care is more complex because they don't have a teacher setting up programs for them and dealing with behavioural issues. I know this to be fact because I was an Education Support Teacher. As it stands today, employed carers receive \$7 less per hour than EAs. Yet, a disabled individual's needs don't change when they leave school. To show they are valued in their occupational role they should be paid the same as Education Assistants. This would:
  - Make the caring role as a vocation more attractive and valued.
  - Existing carers would be more inclined to remain in the carers role instead of seeking employment elsewhere
  - Stability in the workforce would create a less disruptive environment for the disabled individual and their family
  - Availability of carers would enable primary carers to pursue employment.
  
- **Post School Option Funding.** This is the 'backbone' support which supposedly could enable a primary carer to be able to enter the workforce. Unfortunately, the top amount is sadly lacking - \$22,300 offers the primary carer 15 hours a week, 3 hours over 5 working days. This can be topped up by another funding agency HACC which could then give you 4 hours a day. But when you care for someone 24/7 you need that time to do what normal people do when they're not working. ie domestic routines etc. This system needs to be reviewed with consideration given to:
  - Increase funding –
    - so that employed carers can be paid in line with the amount of assistance given to the disabled individual.
    - To cover working hours ie 8.30am – 5pm
  - Outlaw funding 'erosion'. PSO funding has to be handed to an agency recognised by the Government who then proceed to take a % to cover administration costs and employee carer travel.
  
- **Superannuation**
  - Consideration should be given to families who will be self funded retirees. Carers don't have normal lives, their choices are limited. *My daughter's health has forced me to retire early thus affecting my 'super'. My husband has had an emotional breakdown and continues to struggle. He is only 54. He knows he won't be able to continue to 60.*
    - Carers who lose the capacity to work should be allowed to draw from their super without being taxed.
  
- **The role of the carer should be respected by the medical profession and Mental Health personnel.**
  - Carers should not be left with a feeling of being 'fobbed off'. If a carer has concerns they should be explored not dismissed.
  - All drugs prescribed for mental disorders should only be considered as the last possible resort.
    - Unfair 'Funding Criteria' should not be a reason for a person being medicated. This is a human rights issue.

- Carer assistance should be the first priority and this should be recognised by Mental Health. *As it stands now, this Government Department is a 'legalised, drug pushing agency', which administers drugs to vulnerable, innocent individuals. The side effects of these drugs bear strong resemblance to street drugs.*
- Carers should have a legal right to be told of all possible side effects and withdrawal effects of any drug administered.
- Personnel prescribing these drugs should be held accountable if this is not done.
- Carers should be given 'Net' sites to visit (not just pharmaceutical handouts) prior to any drugs being administered so that unbiased, educated and humane decisions are made about their use.
- The rights of an intellectually disabled individual who cannot explain pain, feeling etc, should have special rules put in place to protect them.
- Carers should be told that, "Intellectually Disabled people (especially females)" are highly susceptible to developing severe and irreversible, side effects.

*Our daughter's experience with Mental Health "therapy" has had a devastating effect on our family. It is because of these Government Policies that our social and economic participation have been compromised.*

**Strategies:**

- 1. Increase funding for respite.**
- 2. Increase funding for accommodation**
- 3. Introduce an option for part time accommodation**
- 4. Review 'Mental Health' practices re: intellectually disabled.**
- 5. Review the rights of carer re: medical treatment given to the intellectually disabled**
- 6. Superannuation non –taxable if carer forced to retire due to stresses of caring.**
- 7. Review PSO funding criteria to include all aspects of an individual in need.**
- 8. Employed carers should be paid the same as Education Support Assistants.**

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely

Dianne