

A.O.C. 1/7/08

COMMITTEE SECRETARY

FCHY

Subject: Better deal for Carers and Disabled People

Dear Secretary.

We are the parents of a 16 year old girl who is severely disabled with cerebral palsy quadriplegia, epilepsy.

We have cared for our daughter daily for this time with no respite as we don't trust the services provided to give our girl the care she needs on a daily or o/night basis.

The following are some but not all of the points of contention that affect our caring for Victoria.

1. Bonus scheme is a must for the impact it has on the paying off of large ticket items.
2. All funding arrangements should come under the federal government.
3. Once it has been established that a person is severely disabled with no cure available Centrelink should have an active office that looks after these people without the system making the carers into criminals or continuous checking that is not needed.
4. Continence Aids Assistance Scheme is totally inadequate as It is funded now. The \$450 allowed does not cover a third of the needs of the patient. I spend \$250 per month for 9 months of the year to supplement the CAAS payment.
5. Victorian Aids & Equipment Program needs a boost in funding as the cost of a wheelchair (manual) has spiralled to over \$8,000 and the electric far more and the part provided by VAEP has been stagnant for years and if they don't fund half of the item then they don't retain ownership and wont fund needed repairs through the life of the chair.
6. There is nothing available by the government to assist with vehicle purchase or modification. The current State registration rebates are not available to parents who have purchased and modified cars for there disabled children.
7. People must work and there are no options when they have sick children than to take more time than is allowed and lose lots of money and or the job. I am lucky in that my wife is a teacher and works in 10week blocks and so is able to be home on holidays.
8. Those families that are caring for disabled children and are also working should have their tax requirement negated so that the extra money can pay for the w/c, shower/commode, vehicle modifications, bathroom modifications while foregoing government assistance such as carers payment/allowance. EG: If I earned 55,000

per year and paid 14000 tax and I entered an agreement with the government that I don't pay tax but also don't receive any government assistance, I would be able to afford to set up the home and all necessary requirement for the care of my daughter.

9. Allow companies to sponsor disabled children and the amount that they do sponsor should be doubled as tax relief. This scheme should be advertised and companies large and small could make a great difference to the lives of the children and there parents

Any questions you have and I will gladly take the time to answer.

I hope this helps in your committees deliberations

MICHAEL & HONNIE