Submission No. 4.1 (Inq into better support for carers) A.O.C. 28 5 08

26th May 2008

One of our biggest problems financially is the cost of equipment and continence products that are not covered by State or Federal Government funding. We are looking at this from Victoria the others States may be different.

Recently we had to order a new wheelchair and the State government only funds \$8750.00 of the around \$13000.00 cost and this wheelchair is only the basic needs required to relieve pressure areas and to give our daughter a quality of life in the seating that she spends around 12 to 14 hours per day in. Now for the families and or CARERS (and we can assure you we are not the only ones trying to find this extra money) this always adds a lot of stress to the lives of the families and or CARERS and sometimes they have to ask several charitable organisations until this top up funding is found. Sometimes this can take months of continued applications for this too happen. Fortunately we found the money but this was pressure on us we did not need at that time.

Continence is a major problem for us as we have to spend about \$900.00 per daughter per year just to fund the pads that are required over and above what funding is supplied by the Continence Aids Assistance Scheme and part of the funding we get from a local agency. This does not take into account things like wet ones and rubber gloves which we have to provide for paid carers to use. Then because they are incontinent and sitting in a wheelchair and in our case can not reposition themselves without help we have to buy creams and ointments and the like to keep our disabled person from getting pressure areas and which if we did not it would cost Governments more by doctors and or hospitals to treat those pressure areas were they to occur.

The system makes it hard for any disabled person who has multiple disabilities because the CARERS and or these disabled persons are always fighting the system to find the extra funding for equipment and continence products that State and Federal Governments do not fund.

Another problem for a lot of families and or CARERS is that they do not know where to find any funding bodies to help with the top up of funding for things like wheelchairs, shower chairs, hospital style beds, hoists and continence products to name just some of the extra top up monies needed to be found by families and or CARERS.

We would like to once again state that the 25 hours work, study and volunteer including travel time rule needs to be scrapped and that there be only a

requirement that if the CARER is not caring for their disabled person that the care needs of that person is being fully met.