Productivity Commission

Disability Care and Support

To Whom It May Concern

I would like to put forward a suggestion that the current Centrelink rule of 25 hour per week work, study or volunteer including travel time is an unfair impost on carers who are trying to get themselves into a position where they can function at a level of work, study or volunteer that suits their circumstances and allows them the dignity of having to rely less on government support via pensions.

We do not believe anyone should ever be excluded from volunteering if this is what they want (we also believe volunteering should be a basic human right), provided the care needs of the person they caring for are being met. Under the current guidelines how does a person studying a university degree get to do their study placement if it has to be more than 63 days in a year and because of this rule if a person is studying it takes away any option of respite during that period even if the disabled person is being properly cared for. For example if someone is studying Social Work they should do 75 days placement in one year so because of this rule they have to go to a lot of trouble to get the number of days lowered. This rule in our opinion holds back the opportunities for carers to participate in studies even though the policy is for carers to be supported in improving their education. We know this does not affect many carers but it still takes away choices of the types of study that you can do.

My wife is currently employed as a nurse for two shifts per week but we as a family find the times that she currently works difficult. In our case the main work my wife can get is afternoons and evenings including weekends, where day shifts Monday to Friday would suit our family needs much better and if when she finishes her studies she can get a fulltime job than we would be able to survive without a payment from the government. I know this is not always an option for families but in our case it is. If my wife could earn more money we would be less reliant on government and we believe we would have a bit more dignity. The reason my wife is the worker is because

I have heart disease and cannot work even if I wanted to so as a family we chose the system that suits us best.

We have twin very disabled daughters aged 27 who are fully dependent on someone for support in dressing, showering, eating, positioning in wheelchairs and transport. The other thing that happens in our case but not in all families is that our daughters attend a day placement and all study and job placements are usually while the girls are in their day placement but this not taken into account when dealing with Centrelink.

We would never allow anything to take away from the needs of our daughters and find this rule very restrictive in our endeavours to improve our situation even though our priority is for our daughters quality of life.

We have been arguing for this rule to be changed for about 5 years and find that when we talk to the bureaucrats we cannot get them to understand what our frustrations are because we have been told that this rule is for the benefits of the person we care for but we find this wrong because we and most of the families we know would never jeopardize the quality of care for our loved ones and we are trying to provide a better mechanism to fund the needs of our daughters as not all their needs are funded.

When you have very severely disabled children you are always chasing your tail trying to fund things like continence pads and top up of funding for shower chairs and wheelchairs and other equipment and many time over the years we have had to go to service clubs and the like to find funding for some of the girls equipment and I am sure most other families who do this find it intimidating, that is why if my wife could finish her studies and get a full time 9 to 5 job than we would avoid the embarrassment of asking others for help for the basic equipment needs of our children.

One of the most basic needs of families like ours is a vehicle capable of transporting wheelchairs and most of the families I know battle find the finances or ask for community support for this basic need for our children.

We currently drive a 15 year old van with over 300,000 kilometres on the clock and cannot see a way to replace this in the future and government funding does not allow for support in replacing vehicles. They will fund some of the equipment like wheelchair lifters (Hoist) and lock down points for wheelchairs. This is another reason why as a family we will be better off when my wife gets fulltime employment because our disposable income will be better and we could borrow money for a much better vehicle. Maybe there should be an option of a low interest loan funded by the government and have payments made instead of receiving your carer allowance.

We also believe that to stop the blame game between state and federal governments and to create equity between the states for all families that all disability funding should be federal but possibly controlled by the states as they already have the structures for running it in place, then any packages would be able to move from state to state instead of if you move interstate in some cases you have to go back on the waiting lists in your new state and this is unfair. The equity needs to come in because the needs in Victoria will be the same as in N.S.W. so the funding should be the same for all states.

Yours Sincerely

Ian Radford