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Mum, and myself, care for my severely disabled sister who has Cerebral Palsy from birth. She is now, nearly 29. We fostered her from a government institution, (who advertised on the television for a family, to take her on) when she was 4, when she was 9 we adopted her.

She is totally dependent. Needing care with feeding, showering, dressing, transfers from wheelchair, toileting, grooming, etc. Since I was 16 years old, I am now 41.

My mother is 64, and has her own disabilities due to arthritis.

We fostered my sister from a Government Institution, when she was 4, and adopted her when she was 9. She is now 28 (nearly 29)

In that time, we have had very little government assistance, in caring for her... Funding for equipment, respite, and in home care, has been a very stressful, and often fruitless, endeavour.

We were told countless lies, or misinformation, by various government departments, bureaucrats and case workers over the years. Getting to talk directly to Ministers or any Politicians is a joke... As they only want to converse with the various government run departments who tell their own tales, to cover their own backsides.

We have had to "Scratch and Claw" and Beg... for every little bit of help, and if you dare ask for more... the attitude of the powers that be, is "you already have something, how dare you ask for anything else"

This Mentality, of "more for us, less for you" has to be stopped. It has become very clear to us and I dare say, all other families providing care that disabled people have no real rights, in this so called, FAIR GO Country...

And family carers also have no rights, no respect, and no compensation for the fact that we have sacrificed our quality of life, to accommodate the people we love.

Family carers (old, or young) are expected to give up all their time, and skills, for a pension, or part pension if you are able to do some paid work. Whilst, anyone working for the government is entitled to huge salaries, superannuation, rostered days off, paid annual leave, and sick leave, access to company vehicles, etc.... Often these people do not even work a full 38 hour week.... As opposed to the unpaid family carer, who works 24/7 365 . For a pathetic pension.

Why, is there no opportunity for family carers to be able to buy/build/renovate appropriate accommodation for themselves and their disabled sons/daughters/spouses/siblings etc.??

Why, is there no scheme to fund families to have appropriate transport???

The Disability Legislation, and Policies of government departments states that "All disabled persons have the right to access the community" How? When there is no funding to buy vehicles!

The whole system in my opinion is "Corrupt" and needs to be drastically changed.

The National Scheme, should be nipped out by carers, and disabled people who are able to communicate, so that it is not something unrealistic, or unworkable.

Carers, need to be able to take a real break from their caring role, without being penalised by Centrelink.

We need to be in a financial position to pay a mortgage, and acquire suitable transport and other necessary equipment, such as wheelchairs, hoists, shower chairs, baths, also recreational equipment, such as swings, bicycles, sail boats, etc.

We should be compensated fairly for our time, and effort, same as any other worker with a proper payment, not a pension... we should get superannuation, and paid holidays.

It's also important that everything is made Nationally so we have the freedom to move interstate without having to lose current supports, and funding.

There shouldn't be any waiting lists, and if there are they should be short.

If we have to keep employing bureaucrats they should be held accountable, and be transparent.

The personal experience we have had with "government workers" is disgusting. One case manager suggested that if there was a "fire in our home, we would have to just leave my sister in the house to die" this comment came after we requested a ramped exit out of her bedroom. The same worker, told us that "we were trying to make a profit, from being carers"

Its quite clear to anyone who's been a carer for a long period of time, that there is absolutely no way anyone could make a profit from being a carer.

This is how "out of tune" the workers of the system are. They have no real concept, of what carers endure, and how hard we work, with no rest.

As a younger carer. I feel there also needs to be much more support, and recognition of younger carers, especially siblings who make a huge difference to making the carer role bearable for parents.

We also give up too much of our own lives. We are just as Financially, Socially, and Emotionally disadvantaged as the primary carer.

All carers, need to stand up to the policies makers, and politicians and demand that major changes happen now.

We are entitled to the same quality of life as all other Australians.

We are constantly bombarded with the catch cry that Australia is the Lucky country... Seemingly not if you are disabled, or a carer for someone who is disabled.

The government can find funding to cater for refugees, and people on the dole, criminals, and making their own lives richer and easier.

Why can they not do the same, for the most vulnerable people in our society???

Are we less deserving than politicians? Law Breakers? Refugees? Beurocrats?

I say we are not, we should be demanding equal rights, we need to make the politicians understand that we are also Voters.

And to get our vote, they need to step up, and do the right thing.