

SUBMISSION

We are family of 4 living in outback NSW, our 15 year old son has a progressive neuromuscular disease that is terminal. He now is unable to walk, his speech is slurred, has Hypertrophy Cardiomyopathy, Scoliosis and various other problems that go with this disease. Mentally he is untouched although I think the incredible tiredness that goes with this disease impacts his mental ability.

WHAT WE NEED AS A FAMILY TO SURVIVE:-

One Stop Case Manager – I deal with that many different people and departments to get nowhere, this would be heaven. They would have to be accountable, well trained and preferably a low turnover rate in the position. When they take holidays there must be another contact to cover the position, so we don't have to wait weeks for the support.

The amount of time I waste in meetings and phone calls is nothing short of a joke and I think that is how some people justify their jobs. When I do get on the verge of getting somewhere the position becomes vacant and may take months to refill. The only time I really get any movement out of anyone is after I go to my MP's office and jump up and down and scream then there is a mountain of meetings and phone calls, then all goes quiet again, until I go back and jump up and down again. It should not be like that.

The current disability services over the years have tied themselves into such a mess that no one is confident about what is or is not available. We need to get rid of the following phrases:- not over 18, is under 16, does not have an intellectual disability, probably not available in your area, not sure who covers that, your not in the system, that position is not filled at the moment.

No means testing - The harder we work to make a future the less help we get. It should not be like that. My husband and I have worked out guts out to purchase a business with a residence attached so that we will be in a position to support ourselves. To do this I work two jobs as well as the business. This strategy may or may not work, all I know is because we have tried to do something positive we don't qualify for any support. My day starts at 6am and finishes after midnight but having a go at this is the only way I could see a chance for a future with a bit of super and being able to give our other child the opportunities she deserves. I would love a regular job but because I have to take so much time off for my son I feel like I am just ripping my employers off.

In July we had to pay \$485.00 for shock absorbers, \$160.00 for a Roho cushion cover, \$31.00 for glide 7 spring shocks and \$165.00 freight. There will be an \$88.00 freight bill for August. These were for our sons wheelchair and that was July, PAPD refused to pay for these as we had ordered them before speaking to PAPD. We had done this as when we rang no one was available at PAPD. When this happens which it frequently does, it means no school and no life for our son until his chair is up and running again and it also means we pay the costs. What really disappointed me here was we had already paid for so much ourselves as we didn't want to abuse the system,

yet when we needed the help it wasn't there. As we live in the outback it usually takes 3 or 4 days to get things here after they are ordered anyway so a delay of a couple of days can mean he is off the road and not at school for a week and sometimes more. PAPD not being available has happened on a few occasion's and we need to make sure any service put in place does not work like this. Over Xmas it cost us close to \$800.00 for batteries and tyres as PAPD were closed for 10 days.

Tax Break – you can claim repairs on an investment property but not on a wheel chair or home improvements required because of a disability. Tax breaks on computers for business but not for a kid who uses it because he can't write.

The current system just does not work. Everyone to date has obviously just been content to let things lie as there has been no political force. People have built themselves little kingdoms where we are suppose to beg for help, that's just not on.

We thought we had everything covered from house, car, mortgage, life and top health insurance. Worked all our lives and paid our taxes and then when we need some government support we just fall between cracks.

With the right processes, follow up and people there is no need for any of the above. There a lot of people currently not doing their jobs and the tax payer is paying for that. We need a system with a bit of flexibility and common sense.

Yours sincerely
Mandy Dell