I am the mother of 12 year old twins. I have raised the following issues several times with various government departments but it always falls on deaf ears.

This is my story:

My twins were born 15 weeks early. Lochlan had a grade 3 bleed on his brain while Connor had a grade 1 bleed.

Lochlan was slow to develop and a diagnosis was made at 9 months of Quadriplegic Cerebral Palsy and Epilepsy with an unknown for intellect.

At 3 years of age and after many many hours of physio, occupational therapy and speech therapy, the extend of Lochlans disability was becoming very apparent. He was showing signs of Oppositional Defiance Disorder and although he wasn't autistic, has autistic tendencies. He would hit and kick and spit for no apparent reason. He would knock me over and continue to kick me until I was unconscious. I have had plastic surgery to correct what he has done to me. But the mental scarring is there forever and I am absolutely terrified of being alone with him.

I begged agencies for help but was told constantly that no funding was available. DADHC offered behavioural management techniques but this didn't work, how can it when you have a child with extensive frontal lobe damage. He has no ability to be reasoned with.

When Lochlan was 9, I was advised of Family Choices. It was made to sound like the ultimate answer if they could find a carer. After another 12 months and Lochlan trying to suffocate his twin and then throwing him down the stairs, Lochlan was taken to Randwick children's hospital. It took 9 large adults to hold him down to sedate him. He picked a bed up and tried to throw it at the nurse. They wanted to discharge him but I refused to take him home until I could get ongoing respite and support. But this couldn't be organised. DADHC took Lochlan into their care and he was placed at a respite house. One of the workers at one of the houses offered to take 12 months leave without pay and look after Lochlan.

Please help me understand why there is little or no funding available for respite for parents and carers of disabled children?

Why can the government afford to set up agencies and contract out care yet they can't provide me (the parent) with assistance and respite?

How can they afford to pay a carer for 24/7 care and give her respite of 2 days per fortnight when I was battling to get 3 days in a six month period?

She gets paid by the agency, a family tax benefit, a carer payment and a carer allowance.

I was not entitled to a carer payment because I worked. I had to work so I could afford to pay for all Lochlans NON-PBS medication (there were and still are not any PBS medications available for a child with these problems), his therapies and private respite because there was no funding available.

So please tell me how fair is that and I am the parent?

and please tell me how they can call this family choices when there is no choice. I have had to give my son up because the government couldn't help us but they offer a huge support package to the outsider for providing the same level of care as the parent.

The government needs to look at how they provide funding because the way it is currently arranged is not fair.