

A.G.C. 10/6/08

From: Karen
Sent: Thursday, 5 June 2008 12:15 PM
To: Committee, FCHY (REPS)
Subject: submission for carers

Hi, I hope this is helpful

Hi,

I am a carer of a 10 yr old with Cerebral Palsy.

The stress of getting equipment is the thing that stresses me out as a carer the most. Thank goodness there is funding for all of the equipment that my daughter requires. I have to reapply for funding every 12 months. Duplicating that should already be in her file & Dr Certificates to be re done.

██████████ has had Cerebral palsy which is a disability for life.

██████████ drives a power chair \$10,000 paid for by the Canberra lions club. ,

A manual chair \$7,500, paid by the Canberra hospital system, Community options, Community Connections & Carers ACT & us. (Chairs are so expensive because ██████████ can't sit up by her self, so she needs a seating system.)

Foot orthotics on both legs \$1000 each, from Westmead hospital.

Standing frame \$ 3.500, borrowed from Therapy ACT.

A lifter, \$3000 from Carers ACT.

Shower chair/ Commode \$3,000 from Carers ACT.

A van & adoptions to transport a power chair, \$60,000 us.

Ramping the front & back of our house & converting a bathroom. \$150,000, us.

Please note these prices are all approximates.

What I need is a single organisation in each state that coordinates all the government monies. One place that I and/or ██████████ Occupational Therapist, can apply to for funding. This organisation needs to understand what is an appropriate amount of money for the type of disability that ██████████ has. Also what type of equipment needs that she will have over her life time.

██████████ can't sit, stand or walk. She goes to main stream school with her brother & sister. She is keeping up educationally with her peers. She has good communication skills. Due to the amount of, distance to, & timing of scheduled appointments for doctors, specialist, Therapists, and education specialists. Not to mention the cost & co-ordination of after school care & school holiday programs. I work casually as a hairdresser. My husband works in the public service. We have no family support as a back up. This gives you some background about me.

Karen