

APC 17/7/08

Submission No. 875
(Inq into better support for carers)

From:

To: Committee Secretary
Standing Committee on Family, Counselling, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
Canberra ACT 2600

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's inquiry into Better Support for Carers.

I am a young carer. I'm 14 years old. I care for my younger brother who has severe autistic disorder. He cannot talk and has learning difficulties.

My role includes bathing him, cooking for the family, cleaning, instructing respite carers when they come over, administering medication, shopping, looking after him while our parents are busy and just generally making sure he's safe and happy.

Although he is sweet, affectionate and generally in a good mood, he regularly self-mutilates, which comes from his frustration at lack of the ability to communicate. It is extremely distressing to see someone you love in so much physical and emotional agony.

I miss out on social activities like outings with friends because my brother needs a lot of attention. Often times when I do go out with friends I have to come home early, or at least on time, and can't make any spontaneous plans with friends because care has to be arranged with my brother beforehand. When I am out, for example, at the movies with some people from school, I find it difficult to relax because of worries and anxieties about my brother.

As for school, my parents often have no choice but to ask me to stay home from school either to watch my brother while they go to a meeting relating to him, or to accompany them to hospital or doctor's appointments to help out.

When I'm at school, I am always exhausted and find it difficult to concentrate on my work. I never get any homework done because when I do have the time I am completely drained, mentally and physically. My assignments are often late or not to a standard I hope for. I often feel bitter about not being able to excel to my full potential because of my young caring duties that take up so much of my time, thought and energy. Then I feel guilty for thinking so.

At school I am involved in many extra-curricular activities such as the school musical and debating. However, these all take a toll on my caring duties and sanity. Sometimes it's so stressful having so much on my plate and I feel so guilty about doing something good for myself that I quit fun activities. They do give me the relief and the break I've been told I need, but they cut short time for schoolwork because when I arrive home after, say, debating, I have to take over from my mum or sister and make up for the time they spent watching my brother.

I've suffered from many minor and one major panic attack that resulted in me being hospitalised. These along with anxiety, stress and depression have plagued me for many years and I see little hope for relief in the future. Not to mention guilt for *wanting* relief!

The things I worry most about in my own future are how the family will cope during my HSC exams, and how I'll be able to find the time, energy and free space to study. About when I become more independent and cannot fulfil as many of my caring duties, for example, if I decide to take a gap year or go on holiday. Finally, I worry about when I move out and leave home, how my family will be able to cope without me.

Things that would help me better manage my time, schoolwork, social life and young caring and family responsibilities are:

More respite care for my brother. We occasionally have funding for respite a few hours a week, where someone comes in and cooks, cleans and cares for him. This simply isn't enough help. We need a break!

Secondly, please make it easier for my brother to find a good school. My brother has only recently started school, although he should have ages ago. This is because my parents are those strange people who want their children to be SAFE and HAPPY, and most schools can't provide those things for him.

For example, most support units and pretty much every special school I've heard of do NOT allow volunteers ie. members of the public inside their walls. They do not allow random inspections by DOCS. They are closed off little prison cells. Would you want your child in an environment like this? A place where a child could be assaulted and no-one would ever know, because the child can't talk and the teachers and aides are the only ones with them? Teachers abusing students, especially vulnerable, non-communicative ones, is not uncommon in Australia. Schools seem to be concerned that volunteers will disrupt the special kids' learning. Because I don't want to swear, I'm just going to say that this claim is total unsubstantiated rubbish. Why conceal them from the community and the world if they've got nothing to hide?

And yes, the above DOES matter to the young carer herself because that's the kind of thing she worries about.

Thirdly, provide more support for the young carers themselves. I don't know what part of the government you're from, but at the moment you've got some awesome programmes going such as camps, workshops and relaxation days. These are a huge help. I'd like to thank Anglicare, Young Carers NSW, Esere and countless other groups whose names escape me for providing these services. Recently however my young carer group run by Anglicare in Sydney was cancelled because funding expired. I'm not sure if you have any control over Anglicare, but please increase funding into government type corporations that provide for young carers, especially those that raise awareness about young carers. We're more common than you think!

Thank you for giving me this opportunity to contribute to your enquiry. I hope you get some accurate info and can put into action some things to make life easier for all young carers out there, and their families.

Yours sincerely

Young carer
Avid campaigner