

Supplementary Submission No. 540.1

(Inq into better support for carers)

BRENDA
WA (Perth)

AOC 26/8/08

I am the mother and Carer of 3 Autistic Children.

Parents are the authority on their children, we are the keepers of all the reports, we are the ones given the verbal instructions and we are the filing systems of our children's lives.

As my children are classified as High Functioning Autistics they "appear" normal and therefore they are lost in the education system.

Due to their disappearance in the system it is up to me and the other professionals who work with my children to carefully monitor they're coping and this is where major problems occur.

If you have a non visible disability you need to act out of the normal to be seen. My children do not, they work tremendously hard to fit in, but the effort it takes to appear normal or average takes its toll and it cannot be maintained for any length of time.

An example of this is my 14 year old daughter who was in a mainstream high school and was displaying signs of serious stress, when I brought this up with the school and education department I was continually told it was normal behaviour for a teenager. The result being that my daughter had a break down and is now unable to continue in a mainstream school or with a standard curriculum and her potential for independent living is restricted.

By the time a Carer comes forward and asks for help the situation is serious. We don't have the time or energy to waste. If I have taken the time to bring a problem to you, then please take it seriously.

I don't need someone to tell me not to worry, or relax or to be told that's normal my kids aren't normal and therefore if they are displaying something that concerns me enough to bring it up – it needs to be investigated.

I have ongoing concerns with the Education system, teaching staff who if they have any training in Autism it is limited, and usually focused on the extreme cases, and the School professionals who regularly appear out of their depth, and not only add to the problems of the students but can actually cause permanent harm

I feel I am not being unreasonable in asking for help in working toward some form of independence for my children when they finish school. To my way of thinking if the work is put in early and the right support is given during school my children will be able to live independently and contribute to society rather than be a drain on society.

It is extremely important that I prepare my children for their adult life, but the system is set up to repair only after there has been a problem.