

AOC 30/11/08

SUBMISSIONS

INQUIRY INTO BETTER SUPPORT FOR CARERS.

Please consider the following.

Our son, Drew is nine years old and has a diagnosis of "childhood disintegrative disorder" which is described as a sudden, late onset of Autism.

At the age of four our son suddenly and without warning began to mentally unwind, losing his speech and displaying autistic behaviours. His condition continues to worsen. He has violent tantrums often hitting out at others, self-injuring, breaking objects, slamming doors etc. He attends

school for special needs children. Recently the school has been suspending him on the basis of safety for other students and staff. Sending him home is dangerous because we have another child James, who is thirteen months old and Drew can be a physical threat to him. Whilst I am at work it is not safe for my wife, Reanda and the baby to be at home alone. The education department is rigid and inflexible and the school is short staffed and short of funds. Whilst disability services have been helping with respite and arrangements have been put into place to house Drew at a local respite home, when he is suspended, returning home at four pm. Reanda has been going to the school most days to help out, making arrangements for James to be baby sat (at our expense). Thankfully this has now stopped as it is not fair or reasonable on Reanda,

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Our situation is dire. I cannot obtain future employment due to the constraints of our situation. \* I work in a sales environment on commission\* which gives me time flexibility but I don't get paid for time off and hardly a week goes by when I am called upon to attend a crisis or emergency of some sort.

I have already given up a promising musical career and my wife is no longer able to work.

Dealing with the grief & loss is hard enough but the physical job of caring for Drew is taking a huge toll on my family.

The availability of respite is sporadic and spread out between various agencies, all of which are short of funds and staff. When Drew is at home, I cannot allow him out of arms reach and must be very vigilant and careful when he is anywhere near his baby brother.

We have not had a proper holiday in four years, we were planning a week away but Drew has damaged the stove and we now have to buy a new one, so there will be no holiday this year.

Some nights Drew wakes up and will not go back to sleep, subsequently we are all exhausted.

My income is too high, a health care card and the cost of doctors' visits & medication meant that we missed out on a flu vaccine. James has a chest infection which he passed onto me. I am soldiering on at work because we can't afford downtime. We simply don't enjoy the same opportunities as others in the community.

I could write a whole book but will conclude by saying that I consider that withholding funds for vital services for people with disabilities is in itself a form of discrimination. They are human and they suffer.

Yours Sincerely