Submission No 202

INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

Name:

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My daughter has a rare genetic condition called "CHARGE" Syndrome, she spent the first year fighting for her life then the next few years in therapy learning to eat, learning to walk etc. She has many physical challenges, for example, she has top half visual field losses in both eyes, she is profoundly deaf in one ear, she has no vestibular system which means that she has no balance and battles with depth perception, she has low muscle tone so her body fatigues quickly, she has a movement disorder, so she needs assistance in the classroom to get her work completed. However, she is a bright and intelligent 8 year old girl that loves school, loves her friends and tries her hardest to fit in and be a normal little girl.

Unfortunately the school funding system is worked out in boxes that get ticked depending on the child's disabilities.

For example, my daughter has bilateral upper half visual field loss, so she cannot see above mid level, therefore she has to look down to see where she is going so that she does not trip over things, but her vision in the remaining part of her eyes is fine and she can see, she is not blind, therefore there is no funding for vision. She is profoundly deaf in one ear, she has an FM system at school so that she can hear the teacher, but she has one good ear, therefore there is no funding for hearing. She has no balance so she is unsteady on her feet, stairs are unsafe, playgrounds are unsafe, but she is not reliant on a walking frame or a wheelchair so therefore there is no funding. She has a movement disorder that jerks her body and her arms around that she needs someone to calm her and distract her from it to get back to the task at hand.

When it comes to applying for school funding there are many boxes that do not get ticked and the child is seriously underfunded at school. These are kids that need a special box to be ticked so that the school that they attend can be sufficiently funded to support them.

My daughter is lucky enough to be attending a proactive and supportive school where she does get a certain amount of funding for a teacher's aid and I am extremely grateful for that, but I'm sure that her funding does not even cover the cost of employing a teacher's aid and the school would have to stretch their own resources to adequately support her at school. In order to get this funding we went through a very difficult, stressful and time consuming process for everyone involved.

There are many children who do not qualify for any funding because of the strict criteria involved. The strict criteria is based on boxes that get ticked not on the individual child and their needs. Unfortunately the schools suffer and in turn the child is not sufficiently supported and this creates a snowball effect and families break down.

I think that if the schools were adequately funded, the child with special needs would be properly supported, the child would be happier, the family would be less burdened by stress and anxiety. There is nothing stronger in this world than a mother of a child with special needs, please help us to remain strong and take a little stress from our shoulders and support our schools. You will reap the rewards at the end of the day with a united, happy bunch of tired families. Thank you for your time and consideration.

Angela Begas