

Thick skin needed to come out of autism closet

Today is World Autism Day. **Caz Collins**, behavioural therapist and mother of a child with autism, looks at the obstacles parents face in getting an education for autistic children

IF YOU are a parent of a child with autism, you realise pretty quickly that you will need two things: a thick skin and a lot of money. The money, to start with, is just to get through the visits to psychologists, paediatricians, paediatric neurologists, occupational therapists and speech therapists for assessments. Then if you are pointed in the right direction you will have to keep paying as your child goes through hours of behavioural therapy, OT, speech therapy, horse riding therapy, auditory integration therapy and you keep paying for the gluten-free and casein-free diet, which costs about R30 just for a loaf of bread.

But you breathe deeply knowing it is for the good of your child's progress. The thick skin part is needed in many arenas; dealing with friends and family who don't understand and who think you are a bad parent; "In my day a child like this would do well to get a jolly good hiding..." you hear them say.

The gymnastics club tells you to take your child to the Special Olympics because he doesn't fit in and even still you take a deep breath, but when you have to fight just to get your child an education, that's when the thick skin really needs to grow.

As a behavioural therapist, I work with children on the autism spectrum. I encounter two kinds of parents: group one has been told by doctors and other professionals not to expect too much from their children. They find some sort of care facility for their kids and are happy as long as the kids are happy.

Group 2 hasn't believed the misinformation from the professionals and who know their children have potential, are capable of learning and who believe the South African Constitution which says every child has a right to an education.

Group 2 parents, of which I am one, having an 11-year-old son with autism, spend many hours hoping our children will be allowed to stay at the school they are in.

"Will they allow us back next year?" we wonder.

We look for any gaps at school where our children may be falling behind and work on these at home. We lend the teachers books on Autism Spectrum Disorder (ASD), we try not to rock the boat too much and we pray.

Our kids are under the microscope. If a neurotypical (without autism) child pours sand on another child in the sand pit, the child gets a verbal reprimand and the day goes on. When our kids do the same thing we are told at pick-up that day there was "an incident" and that other parents would not be happy with what our child has done. This is a mainstream school after all. Good thing for that thick skin.

MORE INFORMATION ON AUTISM

● **Action in Autism:**
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Call 031 207 4858

● See <http://actioninautism.org.za>

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The Government White Paper 6 tells us that schools are moving towards inclusion and children with IQs average and above are entitled to attend mainstream schools.

That teaching will be moving from "making a child fit in" to finding out the child's learning style and helping him achieve the same goals as the rest of the class.

It sounds good. Unfortunately, it's not so easy to achieve.

The teacher training curriculum doesn't offer much in terms of ASDs and I recently saw a text book which incorrectly describes children with autism as having "psychotic episodes" so, clearly, to mainstream our high-functioning children with autism we have a long way to go.

I attend many school meetings with my clients who are parents of children with autism.

These parents, thick skin and all, have the following choices when their children reach Grade R or Grade 1: send their children to an expensive private school (just keep paying, just keep paying) with a personal facilitator (cha ching); send the child to one of 12 schools in KZN which accept pupils with

autism, (but don't expect to get a matric); home school, give up your job to do it and possibly limit neurotypical social interaction for the child; open your own school, to which other parents of children with ASD will flock due to the limited educational choices for their children or, of course hope to win the lotto and move to a country that has better services for children with ASD.

Some of my clients are in mainstream schools. There are some schools where principals continually upgrade the staff by means of training in the field of ASD, then there are others where teachers have been left exhausted, principals frustrated and parents, of course, are left feeling desperate at the thought of how to send their children since things don't seem to be working out at the current school.

I have been surprised at the responses of some of the schools who have turned down teacher training offered at the parents' expense and have simply asked the parents to take the child out of the school. I have had the unfortunate experience of being turned down by several schools because of my son's diagnosis; I have even had my neurotypical son refused entry into a school because of his brother's autism.

Children with ASD are not always model students. They often have sensory issues and behavioural difficulties, but nevertheless they are South African and deserve an education.

Schools are often scared to accept (or keep as the case may be) high-functioning children with autism. There is much misunderstanding about the condition and low training available for the teachers.

The principals and teachers, understandably, fear backlash from the parents of the neurotypical children. They have to answer to the school board and they feel the neurotypical children may not understand a child who is different.

When my child first started in a mainstream school, I too feared the other parents; would they complain about my child? Could they influence the powers that be to have my child removed from the school?

I kept his diagnosis a secret from other parents. One day I realised if I wanted any type



DIFFICULT: When a child is denied access to mainstream schools, some parents have to go the home school route.

of support I would have to come out of the autism closet.

And instead of angry parents who would feel sorry for me or would ostracise me, I found understanding.

People who encouraged their children to help my son make friends, I found kids who were kind and helpful to my son and I let the thick skin drop for just a moment, long enough to see a glimmer of

faith in mankind after all.

Not every child with autism will cope in a mainstream setting, and there is talk that "full service schools" are in the pipeline, but in the meantime there are children who can cope with mainstream schooling.

There are also (a very small number) of government schools which don't say no to our kids.

I am grateful my son has a placement in a progressive mainstream government school and "hats off" to his school as well as the few other schools which give our kids a chance, considering the teachers have had no formal training and little experience in autism.

I honour those teachers, some of whom have taught my son, some of whom have

taught my clients, who go the extra mile because they see the child, and not the limitations of autism.

The ones who emphasise the strengths of the child with autism to build the child's confidence and raise respect among the child's classmates. The teachers who try harder, go the extra mile, who never give up, who say at the end of the school year, "That was

hard work" followed by "I have learned so much from this child and I am so glad he was in my class."

Since it is considered that 1:110 children are affected by autism I can only hope that South African schools will grow in awareness of the condition and will embrace these children who are different – no doubt – but not less.

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Low birth weight link found

LONDON: Premature babies are five times more likely to suffer from autism, a study suggests.

Researchers say they have established a link between low birth weight and the condition. And because medical advances mean the most underweight youngsters are more likely to survive, autism levels could increase.

The study, published in the journal *Pediatrics*, found premature babies were five times more likely to have autism than those born at normal weights.

Autism experts from the

University of Pennsylvania School of Nursing followed 862 youngsters over 21 years for the study.

Lead author Jennifer Pinto-Martin said: "As survival of the smallest and most immature babies improves, impaired survivors represent an increasing public health challenge. Emerging studies suggest that low birth weight may be a risk factor for autism spectrum disorders (ASDs)."

Previous studies have linked low birth weight to cognitive problems.

Dr Pinto-Martin said:

"Cognitive problems in these children may mask underlying autism. If there is suspicion of autism or a positive screening test for ASD, parents should seek an evaluation for an ASD. Early intervention improves long-term outcome and can help these children both at school and at home."

She says future studies would look at links between brain haemorrhage, a complication of premature birth, and autism by examining scans taken of newborns. – Daily Mail

