

Power of saying no to autism's limitations

Parenting them is no walk in the park, but children with ASD need to be prepared for adulthood, which involves tough love, says **Caz Collins**

Humeria*, 4, had made progress. Despite the rough start when she didn't know how to sit at a table or focus on a task, she had responded positively to therapy. Gone were her parents' concerns that she would never talk, as the doctor had told them shortly after her diagnosis of Autism Spectrum Disorder (ASD). Her speech was improving, but social issues were still a problem. She had been having therapy with me and in one session, her brother, Ravi*, entered the room. I gave him a toy – but Humeria wanted it and shouted and yelled for her mother.

Mom entered the room, furious. "You need to stop teaching my child to share, she doesn't like it. We buy three of everything so each of our children can have the same. She doesn't need to learn to share."

Shortly afterwards, the family discontinued therapy, despite Humeria's progress and potential. Their priority was that she was always happy – even at the sacrifice of advancement and independence.

As a behavioural therapist working with children with ASD and a parent of a teenager with the condition, I find myself in a unique position.

Just like the parents of the children I work with, I didn't

always know what the right thing for my child was. I too had my tearful days (and still do) and I too had to put my trust in the professionals who worked with my son. As parents our role is to prepare our children for adulthood.

For parents of children with autism, adulthood looks different from the norm. But we need to take our children to the highest place of independence possible, because, as much as we don't like to think about it, we, as parents, will be dead one day. We aren't always going to be there for our children and we need to do what we can now to help prepare them for that time.

Three maids

Telling those who are trying to teach your child self-help skills, "He doesn't need to learn to make his bed, we have three maids for that", as I was told once, is a short-sighted view.

Being able to achieve a task independently swells our children's confidence and courage to try new things, even if there is resistance at the start to want to try.

Studies show that early intervention is effective for children with autism and research shows that the costs for effective intensive early intervention are 15 to 30 times lower than the costs needed for lifelong support of an adult with autism (to age 55) with insufficient intervention early on.

Yet, sadly, I have been in contact with parents who are willing to ignore this for short-term convenience. Parents who choose not to believe that their children with ASD can improve have cancelled therapy for reasons such as "My cat is sick" and "it might rain". They discontinue therapy because they "can't afford therapy and an annual skiing trip".

They are the envy of many South African families who struggle to provide food for their families, let alone therapy. I am often asked to give advice on parenting children on the autism spectrum. Not all parents like the advice I give as it takes effort to carry out.

Most are genuinely looking for help but others choose the easy way out because it's just too hard. For example, many children with ASD I see have decayed teeth. The answer I am given from the parents is: "He won't let me brush his teeth."

I think to myself: "He is 2, you are an adult, yet the 2-year-old is preventing his teeth being brushed?" Rather than avoid brushing teeth, which inevitably leads to general aesthetic and dental surgery, assist the child in building up a sensory tolerance to brushing teeth.

How much easier to teach a child with ASD personal hygiene than to teach a teenager? But to do so requires persistence and

considerable energy. When siblings are involved, parents of children with ASD don't always think of how their parenting impacts their neurotypical (NT) children (without ASD). When the child with ASD wants to watch something on TV, the NT child must immediately switch off what he or she is watching otherwise the sibling with ASD will throw a tantrum.

Parents who allow this don't realise the message it is giving to the NT sibling: You are not as important to us as your brother with ASD. What he wants is more important than what you want. Parents I have been in contact with over the years have said things like: "Well, his (NT) brother must just understand that he always wants to sit in the front seat of the car."

To the NT child the implication is: "You are second best." Having trained in behavioural therapy in the US and having lived in Denver for



Therapist Caz Collins works with a child, 7, who has autism and attends a mainstream school. Collins believes children can achieve their potential, given the right approach and commitment.

PICTURE: MARILYN BERNARD

seven years, I noticed a striking difference in US and many South African parents of children with ASD.

Parents in this country seem very authority-driven. A doctor says the child will never talk and need to be medicated to control behaviour. Parents accept this. In the US I found parents will make a plan, they will prove the doctors wrong – and they will keep searching and believing until they find an intervention that works for their child.

False hope

In South Africa, many parents follow what teachers have to say about their children with ASD. A teacher I was in contact with this year boldly exclaimed: "Why are you giving these parents false hope? This child will never read!"

With therapy, he has now started to read, despite his teacher's lack of faith in him.

I am a firm believer that all children with ASD can learn. I see this with every child I

work with. This has caused many a conflict between myself and the schools of my clients where teachers say things like: "What am I supposed to do with this child? He is at school five hours a day and he can't read", or "there is no need to teach a child with ASD to count".

It is difficult for parents to believe in their child's potential if teachers don't.

At a recent assessment for a new client the parents pleaded with me to help them deal with their child's behaviours.

I outlined some strategies for the family.

The mother looked puzzled and said the school the child attends, which specialises in teaching children with ASD, had told her she must never say "No" to a child with autism.

Effectively the child's screaming, throwing things and hurting family members had been "taught" as the family had been advised to allow the child to do whatever

he wanted without any boundaries, regardless of the impact on others.

Parenting a child with ASD is no walk in the park.

Many parents I come into contact with give whatever it takes for their children to progress: commitment, reassessment of priorities, surrendering personal plans to an uncertain future, financial support and personal sacrifice – whatever it takes that is in the child's best interests.

But it also takes action to promote change even when it seems impossible. They prove true the slogan: "I'm raising a child with autism, what's your super power?"

Names have been changed

Collins is a Durban-based behavioural therapist and the mother of a teenager with autism, who is in Grade 9 at a mainstream school. E-mail btinterventionsdbn@gmail.com or see the Facebook page Breakthrough Interventions South Africa.

Today being World Autism Awareness Day we focus on Autism Spectrum Disorder. Here are some facts:

It occurs in the first three years of life. Children with autism show marked impairment in social interaction, verbal and non-verbal communication, and limited and restricted interests and behaviour.

It is a neurodevelopmental disorder, and is not caused by bad parenting.

Every child is unique in the way the condition manifests.

There is ongoing uncertainty about the cause, treatment, intervention and prognosis within the condition.

Statistics locally and worldwide vary. International statistics indicate that one in 110 children has autism.

Boys are four times more likely to have autism than girls.

The cost of caring and providing for a child with autism is huge – the child in most cases requires 24-hour care.

Many parents are unable to take their children into public spaces. Action in Autism advocates that early educational intervention is the cornerstone to successful integration of people with autism into society.

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Please help our children today.

All you (didn't really) want to know about gout

Q My foot is swollen and red, and is extremely sensitive when I touch it. I have been diagnosed with gout. What can I do?

A Gout is notoriously painful, causing sudden attacks of severe discomfort in the joints, usually accompanied by redness and swelling.

The uric acid levels in the body become too high resulting in a form of arthritis that can cause severe pain and inflammation. Crystals can be deposited in different joints, leading to a dramatic inflammatory reaction.

For most people, uric acid is cleared from the body by the kidneys, but in some individuals it builds up in the bloodstream and forms microscopic crystals around the joints.

Obesity and alcohol are major contributors, along with injury to the joints, high blood pressure, eating foods that increase uric acid levels, such as red meat and fish. Fasting can contribute to acid balance changes in the body, and so does overeating.

Gout can attack more than one joint, most commonly in the big toe and the knee. Pain is usually rapidly progressive and the sensitivity of the joint increases – even a blanket or sheet over the joint is unbearable.

Duration can be variable and the pain can be recurrent if not treated properly. Attacks last between three and 10 days.

Ironically, the pain is caused by the body trying to remove the uric acid crystals from the joints, resulting in the inflammatory response.

Gout should be treated as soon as possible. The response is usually very quick. Commonly used drugs for this are non-steroid anti-inflammatory drugs (NSAIDs), such as indomethacin, ibuprofen and diclofenac – more recently the cox 2 inhibitors like Celebrex, Arcoxia, Xefo – all with useful effect. The



Dr Darren
The advice in this column does not replace a consultation and clinical evaluation with a doctor.

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biggest concern with this group of meds is the GIT side-effects (gastritis and peptic ulcers). Your doctor will advise on the correct medication.

Maintenance is essential - long-term use of medication is advised to lower uric acid levels, which work by boosting clearance by the kidneys (a drug called probenecid) or by reducing the formation of uric acid (a medication called allopurinol).

Complications of gout are kidney stones, which are created from a build-up of the uric acid crystals. Kidney damage is common in those with gout, but is also a reflection of other problems such as diabetes or high blood pressure. I urge you to take control of this treatable condition by modifying lifestyle factors.

Doctors treating patients for gout should adopt a prevention better than cure approach.