

THE WORLD THROUGH HIS EYES: *RAISING A CHILD WITH AUTISM*

PROFILE



TEXT BY

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The only thing I had ever wanted more than being a doctor was to be a mother. As a medical officer in paediatrics, I would find time to feed the neonates and once even tried to adopt one of the abandoned babies lodged in KK Women's and Children's Hospital. When I finally held my very own firstborn in my arms, brushed his soft, downy skin against my cheek, kissed his little nose, and gazed in wonderment at his tiny fingers and toes, and their even tinier nails, everything was right in my world. He was perfect.

However, when he turned one year old and was neither responding to his name nor speaking any words, I started fearing the worst. By the time he was two, I knew he had autism. My perfect child was not going to have the "perfect" life I had hoped for and envisioned. The very ground we stood on seemed to be crumbling under our feet.

The journey to acceptance has been humbling and transformational in the deepest ways. Accepting that my only child had autism was very difficult. It involved allowing myself to grieve more deeply than I had ever grieved before – more so than the death of a loved one and the loss of personal dreams. I felt as if I had to close the door on my hope of a good life for my baby and it seemed like I had failed before I even had the chance to start as a parent. Being a doctor who has

practised paediatric medicine for more than ten years certainly did not spare me from the brutal nights of crying, questioning and bargaining. It took a long time before I could say I had a child with special needs, and even longer before I could say it without choking up.

SEEKING A "SOLUTION"

As parents though, we often quash our needs in the rush to sort out our children's needs. The urgency of finding help for them supersedes everything else, and taking the time to come to terms with all of it seemed like a luxury we could not afford.

My husband and I threw ourselves into advocating for our son, sourcing for the "right" therapists, "right" school, "right" method and "right" interventions, yet feeling that everything was just so "wrong". Again, the many years of medical training and exposure did not give me any useful insights or advantage. Everywhere we turned, we met with incredibly long wait lists: for assessments, for school placements and for any sort of answer; leaving us feeling like we were languishing in purgatory as our son retreated further from us.

He was initially a very happy and independent child who did not seem to need anyone for anything. He

almost never cried and could spend the whole day entertaining himself. He would laugh to himself over secret jokes apparent to nobody else, and was mostly oblivious to whoever was around.

Desperate for a solution, we tried many interventions, starting with the gold standard – the most evidence-based methods. We started him on occupational therapy so he would learn to be more “compliant”, something I had never dreamt would be a goal for any child of mine. He went for speech therapy, where we practised blowing, chewing and making sounds; we even tried putting vibrating tools in his mouth in the hopes of stimulating speech. We signed him up for therapy with Applied Behaviour Analysis (ABA), which has the most evidence supporting its efficacy. This involved a trained therapist working with him for at least three hours a day. When he was three years old, someone would come and work with him in a locked room, getting him to name flashcards or repeat words. If he was not focusing, and was instead running around, jumping or flapping, they would tell him to stop, repeatedly. If he cried, which he invariably did, they would withhold incentives. Each morning, he would require forceful coaxing to go into the room with them. He would whine and complain wordlessly each day. We also started him in a pre-school with Early Intervention Programme for Infants & Children after an 18-month wait, which used an approach called TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children), based on structured teaching with visual prompts within a structured physical environment. We even explored dietary interventions, systematically removing all the foods he loved.

After two years of religiously adhering to this strict prescription, we had nothing to show for it.

Nothing had worked. I would come home from a gruelling day of work to read the daily journal filled by his therapists. Every entry involved a cataloguing of how long he had cried that day, which ranged from 15 minutes on a good day to hours on not-so-great ones. My happy, though disconnected, little boy turned into a rigid, stressed out and miserable child. All the behavioural approaches that involved teaching our child to stop all the “socially unacceptable” things he loved doing, and getting him to comply and demonstrate acceptable behaviours on demand, took us down a black hole into a world of much misery.

OPENING UP NEW POSSIBILITIES

Finally, our son declared that he had had enough with the tantrum to end all tantrums. Except it was not really a tantrum but the distressed and inconsolable sobbing of my baby, who couldn’t understand why everyone was constantly preventing him from doing what he enjoyed or felt he needed to do to cope with whatever was around him.

We knew we had to find a better way to help him, or we would lose him. Flying in the face of conventional wisdom and years of evidence-based knowledge felt terrifying to me as a physician, but I knew that I had to try for the sake of my child. He was mostly non-verbal at the age of five and demonstrated echolalia. We were gently but firmly encouraged to accept that it was likely we would never have a normal unscripted conversation with him.

After many trials that led to dead ends and ebbing hope, we finally stumbled upon a novel approach that did not involve changing his behaviours, but instead aimed at working on his weak social, communication and relational “muscles” through play – a method



called the Son-Rise Program®. Someone gave me the book *Autism Breakthrough* by Raun Kaufman, the first child to recover using this method. Initially, when I learnt the author talked about recovery from autism, I was highly sceptical and, honestly, rather angry that anyone would make such claims, preying upon desperate parents. However, after reading it, I found that what he wrote had resonated very deeply within me, and more practically, it did not involve any therapists or medications. We then decided to follow the simple instructions and play with our son in the way described, for just 15 to 30 minutes a day. Three weeks later, his teacher asked us whether we had been doing anything differently, as she felt the change in our son who suddenly wants to interact with others. Needless to say, we set off to the Autism Treatment Center of America to learn more about Son-Rise Program®.

This innovative programme looks at autism differently; instead of seeing it as a neurobehavioural problem, it sees autism as a social-relational disorder. Far from being a question of semantics, this different perspective means that those repetitive, exclusive and “socially unacceptable” behaviours are no

longer the enemy. They instead become our way to enter into our child's world. Through joining his behaviours, we sent him the message that we loved and accepted him just the way he was, and that we wanted to do whatever he did just because he loved it. Many well-intentioned friends were worried that we were reinforcing his "stims" (self-stimulating behaviours) instead of redirecting him to more functional behaviour, but what happened instead, is that the more we joined him, the less he needed to do those things. He started to look at us, perhaps initially out of curiosity as to why Mummy was not stopping him anymore but instead doing the same thing, and then eventually out of delight over a shared enjoyment. He started to trust us again, and that was the first step towards building a relationship with him.

EMBARKING ON A BRIGHTER FUTURE

We, as his parents, learnt to be social ambassadors, entering his world by joining in his repetitive behaviours with an attitude of love and acceptance, rather than judgement and the desire to change him. We gave him control over what he and we did, and in so doing, showed him how fun and easy it was to make friends and play with another person. We celebrated and cheered his every attempt to interact with us, as raucously and crazily as

we could, acknowledging the effort he was making, incentivising him to try over and over again.

Then the magic began. Just within a few weeks, he started speaking in sentences, spontaneously asking for what he wanted. Within two months, he created his first poem about a hairless bear, all on his own. And in just six months, my dream came true one Sunday morning when he woke me up, saying, "Mummy, I love you! Will you marry me?" The thrill I experienced in that moment exceeded even what I felt when my husband proposed!

It's been one and a half years since we started using the Son-Rise Program® methods, and we have seen so many breakthroughs that we now dare to hope and dream big dreams for our son once more. Not only does he speak in sentences, conveying his needs and wants, he has also started asking questions and commenting on the world around him. His imaginative play is complex and varied. He is conquering his sensory issues one by one, just with the greater social confidence he has. He is incredibly affectionate, not just with his family members, but also to the amazing people who have come alongside our family to play with him in this special way, six to eight hours a day, forming his personal team of awesome Son-Rise volunteers. We now know first-hand what it means by "it takes a village to raise a child"



and our faith in humanity has been more than restored.

This gift of hope that started with a conscious choice to believe in his potential, against the weight of the evidence before our eyes, made us change not just our attitudes but the way we interacted with him and the choices we made with him. The Son-Rise Program® not only gave us back our hope, but it taught us to parent our son with love and respect.

Learning that his parents believe in him has allowed him to develop the courage to try. The tenacity and boldness as well as the joy that he has shown as he learns to be an expert "try-er" will stand him in good stead, wherever life takes him, and we know he will be just fine. ♦