# Imagine: Children with autism are different, not less

**Source: Shelja Sen, Co Founder, Child First, A Child & Adolescent Mental Health Institute**

There is one part of my job that really fills me with dread – having to share with parents that their child has autism spectrum disorder. There is always a range of feelings that bubble up as they receive the diagnosis. There could be dismay, sadness, guilt, pain and anger where they question and reject the certainty of my findings. But one feeling that lurks behind all that is fear: “Can he be like other children?” “Will he ever be normal?”

My assertions that there is nothing like ‘normal’ and that he can lead a healthy, fulfilling life then seem flaky as the parents grapple with the reality of the situation. I can sense hope seeping out of them as they grieve for their dream child that they have carried in their heart for so many years.

Now they have to learn a very different language and a different trajectory. Thread by thread, they have to learn how their child is wired differently. How he has difficulties in social communication, where simple interactions and conversations might be something that might not interest him at all. How sometimes his stemming, repetitive behaviour or rigidities might make a drive to the nearby store so exhausting. And how they have to get used to people staring, sniggering and judging because they think their child looks a little ‘odd’ or ‘weird’. As a mother shared with me, “This is not what I signed up for when I thought of becoming a mother.”

It can be very tough for parents to work out what is best for their children in the present-day ‘industry’ of autism. Some treatments seem like rocket science, claiming a “complete cure” for their child. Parents in their confusion shunt their children from doctor to occupational therapy to special educators to psychologists to speech therapists to what not to start all over again the next morning. Parents will do the best for their child with the resources they have but, unwittingly, they get caught in this senseless circus.

Am I saying that parents should stop all therapies and just let it be? Not at all. All I am saying is that we need to stop the approach of “let’s fix” the child. The child is not damaged or broken so nothing needs to be fixed. Maybe we are bit broken as human beings that we struggle to accept children who do not fit into the neat grooves we design for them.

Can you imagine how it would be for a child to sense (and each child can sense that, no matter what the level of ability) that there is something wrong with him fundamentally? Irrespective of the severity of the condition, living with somebody who wishes you were different at the core is much more damaging than the condition itself. It is toxic for the relationship and their emerging sense of worthiness.

Neurodiversity is a term that was introduced by Judy Springer from Australia who is on the autism spectrum, and so are her mother and daughter. As she put it, “I was interested in the libratory, activist aspects of it — to do for neurologically different people what feminism and gay rights had done for their constituencies.”

Neurodiversity culture now has a huge following worldwide and their basic belief is that autism is not a disorder or an illness but a way of being. Though we have different views on how the hardcore activists in the neurodiversity and the autism rights movement culture are against any form of therapy as they believe “we are autistic and we are fine as we are”. Well, if this means that the child gets gridlocked into the disengaged, at times self-hurting cocoon of repetitive behaviour, then I take a stand against it.I would, therefore, take a middle path of neurodiversity, which is about:

**Awareness and acceptance**

For building awareness, you do not need to be an expert on autism. Let’s just try to remember that each child is wired differently and if you see a child who is behaving atypically, then it is alright. There is no correct or right way for being in this world. A child might scream to communicate, another might like to fiddle with his fingers as he jumps up and down — there is nothing wrong with them. You might like to spend hours bingeing on Netflix (no judgment) and they like to do their thing. To each his or her own. According to current studies, one in 59 children are on the spectrum, so the chances are high that you will be lucky to meet them in the mall, in your park, in your children’s classrooms or even find them in your homes. Let go of any notion of ‘normality’ and you will be amazed at how fascinating and colourful this world is.

**“I am a child and not a disorder”**

If you are a parent of a child on the spectrum, remember you are the expert on your child; not the psychiatrists, psychologists and all the therapists. Early intervention is obviously most effective but your child needs you more than all the best of treatments you might have lined up for her. Make sure you have enough one-to-one time which is not about teaching but just about connecting and having fun. Enter your child’s world and play. Let go of all your preconceived ideas of play and just be. Play with the trains, roll on the floor, line up the cars, stack the boxes, ping the bubbles. Make sure the child gets the message that you love being with her and value who she is at a cellular level.

**Grow your tribe**

It takes a compassionate village to raise a child with autism. Find people who understand your struggles and yet can celebrate your child. At times, it is the amazing therapists who are rooting for your child at every step, or your elderly neighbour, family members, a teacher, or what we are relying on more and more nowadays — an e-community. We need to build emotionally safe spaces for children where they are accepted and welcomed for who they are.

**Take care of yourself**

Let’s admit that parenting is exhausting and parenting of children with autism can be even more exhausting. Some basic skills like eating, dressing, speaking, walking and running that might come easily to other kids might require your extra input. As the child might not take to other people so easily, or at times other people do not really ‘get it’, parents, especially mothers, end up spending all their waking hours taking care of them. A mother once shared with me, “I feel guilty even if I go out with my friends.” So let the guilt go, it’s not going to help you or your child if you deplete yourself to the ground. Like all children, even your child needs a mother who is healthy and happy.

**Advocacy and not apology**

Temple Grandin, who herself is on the spectrum and an advocate for people with autism, remarked, “I am different, not less.” We need to stop apologizing for our non-neurotypical children. Yes, they can be odd, at times weird, and they might test our patience and need us to bend our reality in a way that leaves us drained out. But more than anything, they help us grow and face our prejudices and biases and become more humane and compassionate beings. So next time a relative rolls his or her eyes at your “badly behaved” child or your child’s teacher tells you that he is “not capable of learning”, take a deep breath, smile and tell them, “He has autism and he experiences life differently. Let me know if you want to learn more about it.”

I love how Andrew Solomon, author of “Far from The Tree” sums it, “Though neurodiversity activists can get in the way of science and sometimes wrap themselves up in self-important, specious arguments, they also light the way to such love — a model of social acceptance and self-acceptance that has the capacity to redeem whole lives.”