

Irony & Conflict

Compiled by Arya Baskar

It is never easy to be the parent of a special needs child. It is not a job that one signed up for knowingly. Sure, I heard those jokes about babies not coming with instruction manuals. But you were following the path of thousands before you. What was the worst challenge you were going to face in raising a child - a rebellious teen on drugs?

The initial news of your child's diagnosis is an unexpected tsunami. Everything unravels. There is no buttering down the incredibly hard journey that's ahead. It's a maze within a maze. Sometimes the mazes are easy to solve (kids improve) and sometimes they are not (dejection and frustration)

Raising a special needs child is a bit like climbing a slippery slope. You take 2 steps forward, slip one step back. You don't know if you'll ever reach the summit, but you have to keep trying. And at every ledge, you have to remember to pause and rest and re-check your ropes. If you are lucky you'll make it to the top. Or the summit may be the beginning of another mountain, who knows.

But I think while trying to climb, we shouldn't forget to help our fellow climbers. We shouldn't forget to enjoy the climb. After all, the journey is more important than the destination.

Many people with typical children may take a long time to get any perspective or may never get it. No one enjoys a free moment more or laughs at a bad situation more or cheers their child's smallest steps more loudly than a special needs parent.

More ironies

- We need to spend more while not having as much time to earn more.
- We constantly need to fight the system that is supposed to help us.
- We need to give more while needing more.

Reality in life is that we are parents of children with special needs.... we are 'Special Parents'. Let's rant and vent.

We are often charged premium prizes on the smallest of services or products – special prizes for our special kids and we invariably feed this phenomenon. Strange as it may seem, we the parents, may have helped drive prices higher. In defense of us parents though, we are very emotionally caught up with our special needs kids - most just bewildered and we have no standard roadmaps to follow (unlike typical kids). We end up buying all sorts of useless things for lots of money. Our need for a product is not really linked to the kid's age - it's about when we learn about it, or we hear success stories about it or when we get into those periods of frustration that we are willing to try anything and everything or when some therapist insists our kid absolutely needs it. So how does one coordinate a need for a special needs product with enough interest in that product at a point in time in order to avail of group discounts. The irony here is that there is no one treatment that works for our kid so we have to try them all on the off chance that we may stumble on one that works for our child.

It's almost like we try to assuage our guilt at the difficulties our kids face by spending a lot on them. We act far from logical and rational when it comes to them. I would shop around for the most cost effective furniture for my home - but if some therapist tells me that only a certain kind of thing suits my kid, I may be willing to spend thousands on it – on the chance that it would somehow make my kid "ok". Many households have had to become one parent earners due to the demands of our child's needs, reducing our income potential at a time when we need more to spend.

Even as we are trying to unravel the issues with our children, we are also struggling against a system that is supposed to help us. It's about funding for services, it's about the quality and quantity of services and support, it's about getting a classroom that's appropriate for our child. At times it almost seems like we fight to get our children the right to an education, in a country that guarantees access to an education for all. The prefix “special” in the context of education and potential, somehow is subject varied interpretations,

misconceptions and confusion. The saddest part is that many who have been in the system for a while become very set in their thinking and this gradually erodes their ability to see the potential in our kids, especially as the kids get older.

Our job description is that of 20 jobs, with being a parent (the way we understand a typical parent's role) just being one tiny portion of it. We have to be a therapist, educator, advocate, recruiter and trainer, doctor, dietician, massage therapist, researcher and much more. We have to work with little emotional support as such a complex situation is unfathomable to the parents of most typical kids, which makes them unable to relate. All this takes its toll on us socially, physically and mentally.

Yet, something intangible happens to you along the way on this journey. Your thinking and perceptions change. You develop unexplainable levels of patience, tolerance, empathy and humility. Ironically your growing bundle of "special" is what brings about this transformation in you. Our kids are "special" in just so many ways.

Ok, I didn't ask to be the parent of a special needs parent, but hey, I'm gonna do my darnest best at being one ;-)

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