

PERSPECTIVE

Just another mom- The fight against exclusivity

Being told that your child might not be able to walk without support isn't something you can ever be prepared for. And that pretty much describes what I often feel; out of control, unprepared, trying to reinvent a solution every time in my role as a parent to a child who is differently abled.

Saharsha, now three, was diagnosed with cerebral palsy when she turned one. Cerebral palsy is an umbrella term for a condition that limits a person's ability to move. The neurologist got off from his chair and walked with an exaggerated gait, showing how the legs might scissor if Saharsha eventually learns to walk. And with that diagnosis, we were left out in the cold in Singapore with a recommendation to go for physiotherapy to teach Saharsha movement and occupational therapy to help her to cope with day to day activities.

My husband and I survived the diagnosis. It gave us pain, made us angry, we cried, we screamed, we got sad and finally we learnt to accept it. But that was just the beginning...

In the Asian sub-continent, we are often conditioned from an early age to only talk about our strengths.

'Strengths' are meant to be shared, bragged about, while 'weaknesses/flaws' are personal, and need to be carefully dusted and hidden under the carpet. And that's what I also did in that first year when we found out about Saharsha. For that one year after Saharsha's diagnosis, I 'fakebooked' about my imperfectly perfect daughter. We were living in Sri Lanka at that time and I only posted carefully selected photos of her sitting and not the remaining 95 percent when she would topple over as she lost balance when unsupported, and of course never standing as I didn't have any of those...I only felt at ease talking with my immediate family or closest friends about it.

At the same time, Saharsha continued to grow into an incredibly happy child, living up to the meaning of her name 'joyful' in Sanskrit. When most other children of Saharsha's age could do whatever they want, Saharsha needed my help to even get out of bed. She can only walk with a walker, but needs help in her transitions of getting in and out of it. A simple task like brushing her teeth requires perseverance on her part as she needs to work on her core to balance and sit and keep her hands steady. While children of her age can play around to their heart's content, Saharsha leads a much more carefully planned life filled with physiotherapy, swimming, occupational therapy, personal training, speech therapy, and soon, horse riding. And yet, she finds joy in the littlest of things, and is full of enthusiasm for life. That was the time I had a realisation: I could either shy away from facing life, and pass on society and my own inhibitions to my child, or I could take the cue from her and teach her that just like everyone else, she too can

achieve anything as long as she works hard for it.

It is still a tough ride especially since people tend to point out our 'differences.' I was once walking with Saharsha and her younger sister Anwesha, both girls were in the highest spirits chasing each other when a lady came up to us and told Saharsha how deeply sorry she felt for her. My three year old looked at her in utter confusion. Similarly, I have had people telling me how sorry they are, and that they will pray for Saharsha and of course my favourite, 'She will become normal.' I mean for the hundredth time- cerebral palsy is not a disease, it's a condition and can someone really define normal? For us, this is the only life we know. Sure, we need to make small adjustments, but it hasn't stopped us in anything.

Saharsha has already travelled to over a dozen countries with her walker, right from getting a surgery done in America to feeding the giraffes in Kenya to eating the best congee in Vietnam to building sand castles in pristine Fiji. Who said I wanted 'normal'?

Thus, we also started to document Saharsha's journey through an Instagram account, 'Chronicles_ofZhazha'. It began as a way to document our incredible journey. Soon enough, our followers started increasing and Saharsha's love for dressing up made us start brand repping for clothes for a few American and Australian small shops. Through the Instagram account, we started advocating for inclusive fashion. We wanted to show that you can be fabulously cool, brave and happy in a walker just as without it. I hope that one day we will see more ads that include children who are differently abled and instead of saying 'Wow, that brand has

a child in a wheelchair' we don't even bat an eye as that becomes the norm!

We are very normal people, maybe living under extraordinary circumstances, but we hope to give Saharsha the confidence to stand up against bullying and any other prejudice that will come her way and also realise that she has the fullest ability to reach her potential and live her dreams. That girl whom they said might never be able to walk, has started walking with sticks and can balance herself to stand for a few seconds without any support. Anything is possible.

By Nabanita Sen Bekkers

Photo courtesy: Nabanita Sen Bekkers

Follow Saharsha on Instagram:

https://www.instagram.com/chronicles_ofzhazha/



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