

I have spent some time reflecting on the past decade, now that our twins are 10 years old. It has been a time of lots of blessings and growth. The growth has not been just for the children, but profound growth for us, as parents too. Many families that we have become friends with over the years flash through my mind. From all these families we have gathered inspiration, support, hope and strength.

All of us had to cater to the needs of the special needs child while going through the phases of denial, guilt, grief, anger and acceptance. With renewed strength we have all been able to find therapies, advocate, and network and do what is best for our child at that time.

Jeena has brought many families together and

hired live-in nannies. Some moved to India for support while others moved to the U.S. from India hoping to get better integration. Some moved to different states within the U.S. for better services, others, moved to California. Some chose to home-school their child or tried private schools as an alternative to the public school system. Some hired lawyers to advocate for better services in public schools, while others seemed satisfied with whatever services they received. They kept trying different things at different times. Despite all this chaos, many shared their knowledge with other parents thus empowering new parents and themselves.

Over the years, we as a family have also found people in the community helpful and understanding. The school system, therapies and awareness in the

Reflections

on the decade

By Uma Raghavan

provided a safe place for children and their families. Through Jeena, we have learnt that every family is unique; how they balance their life with a special needs child is different. There is no one right approach. It is an evolving process and each family has to find that balance.

Some of families were able to take care for their special needs child, even as they maintained their ski trips and outings for the other children in the family. Others modified their family activities to what the special needs child could also participate in. Many others split up the roles – one parent dedicated to the special needs activities and the other parents to that of the typical siblings. Some tried therapies in sequence, while others tried many therapies simultaneously. Some tried out-of-the-box therapies while others stuck to traditional therapies. Some integrated the child's activities into just their daily routine. Some had extended family live with them. Some had one parent quit work to attend to the child's needs, while others

community has overall been accommodating. Again this is an ongoing process. If someone makes an unhelpful comment, we have learned to not take it personally. We have learned to use it as an opportunity to provide information so we can increase their understanding. The instance which especially touched us was when about 15 kids from the general education class showed up for our daughter, Nitya's birthday. And they brought her such thoughtful gifts – a pompom, a doll with long hair, water bottles filled with color and glitter, peg puzzles, etc. These children were thinking about her favorites and were overjoyed at seeing Nitya enjoy those things. On the other hand, we also faced instances of great negligence, such as when Nitya was left on the school bus for 2 hours, before she was found strapped in her seat, which appropriately got the driver fired.

Reflecting on the past decade for our family, I could find instances where we invested in therapies that proved hopeful and others which were unhelpful yet

drained our pockets. After the initial disappointment, it helped us understand our child better. I would question- Why didn't the therapy work? Was I targeting a step too advanced without looking at the baby steps? Every disappointment brought me one step closer to finding better solutions, now that I had additional knowledge about my child. For Nitya, intensive behavioral feeding therapy for 3 months got her to oral feeding completely without depending on G-Tube. So there were instances of therapy that worked wonders. Then there have been times when we have rushed from one therapy to another and when the children didn't do well, I have blamed myself for doing too much. There have been times when I didn't do many therapies and have blamed myself for not doing enough. At other times, we have been just content with whatever we were doing at the moment.

Now Nitya has the mind of a toddler in a 10 year old girl's body, so this comes with its own challenges now and in the future. Toilet training is the next big step we are working on, which needs my constant attention. But we will take baby steps and help Nitya get to the next step. If there are worries about the future, again, we look at it from what we need to plan now, so that the issue is addressed. Due to her vulnerability, there are certain issues that we can only address as she grows. Lessons from past mistakes guide us in a better direction. Needless to mention, is the day-to-day stress it adds to our life. But we have found our ways to cope, either by connecting with friends or by seeing the bigger picture. I try to center our life around the kitchen table where Nitya can listen to music on my computer or her DVD player and her brother can do his homework while I am cooking. This way I can find her as soon as she wanders off. We sing songs, listen to songs, play games and have a busy, engaging evening and take things as they come. With this mindset, there is always contentment.

And contentment is needed to have a peaceful, balanced family.

