

The Long Road to Acceptance

Sita Krishnamurthy

Almost all of us in this world are brought up to aim for comfort, money, status and enviable careers. There is no room, or even a passing thought, for a special-needs person in these plans, either as a parent, or a sibling or even a teacher. So, when a child with a 'disability' is born, parents have great difficulty accepting it as special-needs children were not in their life plans. Statistics show that for every 59 live births, one child has the Autism Spectrum Disorder (ASD). However, other disabilities, such as intellectual challenges, spasticity, learning disability (as known in India), Down's Syndrome (DS) and hyperactive disorder are comparatively lower in incidence.

Parents are not adequately prepared to deal with the needs of children with disabilities (CwDs). They get plenty of 'advice' from well-meaning friends and relatives. Those who are educated resort to *Google* but good, meaningful information and support systems are completely lacking.

Given the miserably inadequate infrastructure support available even in large cities, children with disabilities (all types) are accepted in special schools that cannot cater to specific needs in terms of therapy and training. Mainstream schools that practice inclusion also have a very difficult time because neither enough knowledge nor sufficient training is given to the teachers. However, the biggest concern for special schools and parents of CwDs remains the lack of awareness in society.

My observation is that society has impeded our goals for children with disabilities by rejecting them. Over the years, we have had to redesign our curriculum to bring CwDs as much as possible on par with the neuro-typical population. What makes people look down upon, fear, dislike, even reject persons with special needs?

Academic qualification, special skills and economic status do not seem to matter as much as the ability of CwDs to socialise and communicate. At the Deepika School, we have been working towards improving these skills and trying to mainstream CwDs into society. As the saying goes, charity begins at home and, as a first step, we

have to empower the teachers in our school to develop and strengthen their own personalities and capacities. Exhaustive training is given to all the special educators both in teaching and in soft skills. The support staff – the men who drive the school vehicles, the administrative staff – are all trained to love and accept the children as they are and support the school in achieving its goals.

Our journey

When I was teaching in a mainstream school, I was unable to comprehend Mamtha's* inability to understand or remember for more than a few seconds, what was being taught in class. Dinesh* would smile angelically but would neither talk nor participate in any activity, however exciting it was for the other children. The constant 'why?' in my mind led me to discover a whole new world that has given nothing but joy and a sense of satisfaction.

When we started working with special children, we only had one issue to deal with – slow learning. The children could sit quietly, pay attention and learn with enthusiasm. Teaching them was cakewalk. They had excellent social and communication skills. They had problems only with academic learning. So obviously, we were not prepared for what we would be facing in a year's time when from three students, we jumped to twelve. Now, the students had varied problems from Hyperactive Disorder to Asperger's Syndrome! And this was in the times when Asperger's Syndrome was practically unheard of. We were clueless, Google-less and had no experience of working with autism.

The hyperactive Arvind* hated reading and writing and the moment he sat at his desk, he would start tapping his feet under the desk and tap with his hands on top of it. This was the signal for other children to give up what they were doing and follow suit! We wasted precious hours running behind him. The only repertoire of words for Vishal*, a child with autism, was a long list of TV channel names which he would repeat continually. At that time, in our ignorance, we did not know that he was trying to communicate. We could not know Sneha* was struggling with hypersensitivity

to sound when she sat with her fingers in her ears. Evidently, we had plenty to learn. We met senior special educators, doctors and as many specialists as possible in the field of disability. We attended seminars and conferences around India to broaden our knowledge. Unfortunately, we only learnt the prevalence, the whats and the *whys*, but never the *hows*.

Not just Arvind, Vishal and Sneha but the several children who had been rejected by the mainstream schools had to be helped. We were not blaming the mainstream schools. They did not know what to do, let alone *how* to help. Understandable, considering we ourselves did not know it then!

The lessons we learned

We bought books on different disabilities but none of them seemed to apply to the Indian children. That is when we realised the importance of observation. An unbiased and keen observation and an objective analysis of the children gave us many insights into the world of CwDs, especially, those with autism.

We realised that physical activity and regular exercises helped not only their motor development but also helped them overcome some sensory problems. Self-help skills and personal hygiene, hitherto expected to be parents' responsibilities, needed to be taught and monitored.

Teaching the children to understand and speak English became a huge challenge since students were from multiple states and had difficulties with even their mother tongue. We had to resort to miming and sign language to be understood since we ourselves did not know their language or dialect. There was Koushik* who would mouth a stream of words whenever he had to speak which we thankfully did not understand as we later learned that he was spewing out only abusive words!

Then came the challenge to help the children understand, recall, analyse, apply and generalise. The tasks for every learning process had to be analysed and sequenced. All academic learning and vocational training depend largely on cognitive skills. We need a lot of planning and creating activities to improve our children's cognition. We discovered that with appropriate training it is possible to improve children's understanding to some extent and give them a feeling of achievement.

However, none of the above was possible if we could not work on their social and communication skills, especially as when students became teenagers, there would be a major shift in behaviour and mere

cognition would not be enough. All our efforts over the years would be in vain if the students developed negative behaviours and could not be trained in a group. If acceptance had to happen, we had to concentrate on the soft-skills.

The home run

When we moved into larger premises, we slowly introduced the therapies needed: speech therapy for the non-verbal kids and for those with difficulties with speech. A very gentle and compassionate paediatric physiotherapist set up a unit and helped the children with motor requirements and sensory integration therapy for students who were hypo- or hyper-sensitive to light, sound, touch, smell and taste. A well-equipped occupational therapy unit was also set up with the help and support of parents.

All this took care of their physical needs. The students now needed to learn acceptance and sharing, joy of living, appropriate and acceptable socialisation, culture, self-expression and much more. Music, dance, art, craft and cooking became integral to learning. Arts-based therapy was introduced as a healing process for specific purposes.



Arts-based therapy sessions

A trip to Belum Caves, Andhra with the children became a stepping stone to one of our major teaching processes. The trip opened up vast vistas for multiple teaching techniques. Children learned to search for trains, book tickets, calculate money needed for travel and accommodation, etc. Socialisation and communication happened naturally. Self-help skills and personal care took an

upward swing. It also added to their knowledge of history, geography and math. Every year, students went on excursions - first for short trips as preparation, then for longer trips of two weeks or more.

Of course, it has not been easy. We found a number of children were still bed-wetting, did not know how to bathe or possess the basic courtesies of using the washroom. Some were choosy about food, some would stay awake all night...the problems were endless. On a long trip, fifteen-year-old Rajeev cried his heart out at night and said he wanted to go back to his mother when the group was 2000 km away!

Some of them displayed amazing skills unexpectedly. A student with Asperger's Syndrome (currently listed under ASD) could read the names of every station and river that we passed even when the train was running at full speed! Some boys and girls showed exemplary leadership skills and lightened the work of the teachers to a great degree. Another surprising and delightful outcome of all the trips and therapies was the strong values and tolerance that the students developed.

Now we had the confidence to foray into academics and we trained our students to write the Open Basic examinations of grades 3 and 5 held by National Institute of Open Schooling (NIOS), Delhi. Students were also trained to write local SSLC board examinations and the secondary level examinations of NIOS. With the confidence born from the success of the above examination results, we have ventured into teaching for senior secondary examinations and skill development training for those who cannot continue academic training.

Today, a typical day for young students starts with prayer and chanting, Brain-Gym exercises, classroom learning interspersed with games, physical exercises, art and music. Some of them receive speech therapy and some, physiotherapy. Children in the autism spectrum are also given sensory integration. Some days they have music, dance and arts-based therapy. Weekly outings are planned for play, looking around and mixing with the public.

Older students in the age group of 12 to 18 years are given academic training according to their learning abilities. Those who have severe learning difficulties are started on appropriate and meaningful vocational training. Students who have fairly good visual perceptual skills are trained in multimedia and animation, in the culinary arts,

beautician and hairstyling, housekeeping, laundry, making paper products and so on.

Every year, we design a theme-based show which is well within the students' capabilities. *Tastes of India*, a programme on the culinary arts of India was a resounding success. Students and teachers grouped themselves into different regions of India and produced mouth-watering dishes! A programme on *Swacch Bharath* to showcase the dangers of pollution and the importance of waste segregation was held. Even music and dances based on *Swacch Bharath* were beautifully performed. We had *Dances of India* and *Rhythms of India* to encourage the skills of not only the students but also the teachers. At such times, we see that rare glow of pride and joy in the parents' faces too and the happiness invariably seen in the faces of the children when they do what they enjoy doing and have an aptitude for is very heart-warming.

The facilitators

It is a joy to be with the students who always live in the present. The road to reach this understanding of the needs of special students has not been a smooth one. Each student, whatever the disability, has unique learning needs and a unique style of learning. Being authoritative and firm with them works well but does not come easy for many teachers.

We have to be alert and observant all the time when we are working with hyperactive children. When we work with intellectually challenged children we have to consider learning from their level of understanding. A good attainable goal, but achieved at a slower pace, works wonders with them. Dyslexic children, who are otherwise normal and intelligent, suffer the most because no one seems to understand that it is a neurological condition. Despite several awareness drives in schools, affected children are still subjected to abuse and harassment both by schools and parents. The refrain is. 'Why does he/she not read or perform in tests when he seems to know all the answers?'

'If you want to work with children in the ASD you should have them in your hearts first' is an essential lesson that was given to us at the very beginning of our work with autism. It requires immense love, patience and compassion to understand and train them. Here special educators play a vital role. Their personalities, attitudes, vocabulary and knowledge are very important. They cannot think of this as a job but as an overwhelming need! As teachers,

we have to remember that children are quick to sense our attitudes. While training in specific disabilities is mandatory for the teachers it is only a very small part of the whole training programme. Anyone can pass a training programme and get a degree, but that does not make them good teachers. A balanced personality, emotional stability, problem-solving skills, creative thinking skills, effective communication skills, empathy and good interpersonal relationships are needed. Developing these skills requires a supportive and encouraging environment with opportunities to bring out teachers' creativity. School heads and managements cannot be fully aware of the needs of each of the student, but the teachers are. Hence, we believe in giving the teachers the responsibility to create a child-specific curriculum. The teacher is given a broad framework, but the details of daily training are left to her/him.

More than all of the above, teachers should also be aware of the sensitivities of the children. A high-

pitched shrill voice, sometimes even bright and showy dresses can cause disruptive behaviour in children. We have a regular training programme for all the facilitators and therapists with monthly sessions on developing teamwork skills, learning new teaching techniques and progress in technological devices as applicable to special education. Stress-relieving programmes are also held.

Teaching children with disabilities needs a special approach but is a very rewarding and satisfying occupation. Regular sessions in spiritual development have also proven invaluable. To de-stress teachers, we organise picnics and trips; train them in dance and music; have regular sports sessions to not just relax but to enhance their self-esteem and health. The management does not look at them as mere employees but as resource people who need to be guided and supported regularly – but not supervised – so that they handle special children with dedication and commitment.



Teacher Empowerment Programmes

The parents

If the wellsprings are not cared for and equally nurtured, they could dry up. Parents of special needs children need more care, more compassion and continuous support. When we talk to the parents, we realise how difficult their lives are on a day to day basis. Many do not have any support system. Sometimes a parent does not even have the support of spouse or close relatives. Burdened as they are with financial issues, as medical and therapeutic interventions are expensive, they are not in a position to pay for extra sessions even if those are needed. Both the management and the teachers have to understand them with compassion and empathy. Regular sessions with medical doctors, counsellors and therapists are held for parents.

We can help children only when they have supportive parents. Regular meetings are held with the parents to discuss progress or the lack of it. They are our first line of support and their cooperation is invaluable. We start every academic year with a *Bonding Day* where we organise a day's picnic with the parents, children, teachers and other school staff. Sometimes, even siblings and extended family members join us. Nothing develops the bond between parents and teachers than an informal setting, like a picnic.

It has indeed been a long road to make our children accepted and included. Let us take a pledge that we will turn society around to accept inclusion so that one day there is no discrimination, no rejection - only love and compassion.



Sita Krishnamurthy is the Founder Principal, Deepika School for Special Needs Children, Deepika Vocational Centre and Samashraya Learning Centre for Skill Development. A post graduate in Arts, Diploma in Specific Learning Disability, Diploma in Counselling and Guidance, and PG Diploma in English Language Teaching, Sita has 36 years of teaching experience of which 27 are with special children, specifically in the field of Dyslexia, Intellectual Disability and Autism. She is the Course Director for teacher training programmes in the Information and Resource Centre for Developmental Disabilities, Basavangudi, Bengaluru. Sita Krishnamurthy may be contacted at sita.krishnamurthy@gmail.com