

# Seeing Disability as Diversity

Pranalee Sharma

*'...I had to suffer a lot of mental trauma after Ayan was born. He had asphyxia when he was born. The doctor told me that Ayan would have certain developmental issues while growing up. I blame the doctor for this situation. I was staying with my husband and his parents. They didn't accept Ayan and he was deprived of his grandparents' love and care. For Ayan's wellbeing, I had to leave that house and we shifted to my parents'. My husband works for a company where they organise regular parties. Every time, I take Ayan with me, the other parents take their children away from him. I tolerated this for a while, then I stopped going for these parties. I have now turned into some unsocial being just to save my child from social neglect and isolation...'*

This is a snippet of a case study of eight-year-old Ayan diagnosed with developmental delay, who was attending the inclusive Rajkumari Amrit Kaur (RAK) Child Study Centre, a preschool in Delhi in 2012. Ayan attended two different schools before being a part of RAK Child Study Centre. Teachers of both the preschools asked Ayan's mother to withdraw him as he was a 'misfit'. In 2012, Ayan had already completed three years in RAK Child Study Centre and, according to his mother, he was thoroughly enjoying his time there.

The mother became concerned about his future after RAK Child Study Centre. By then, Ayan was already eight-years-old and he was supposed to enter formal school the next year. Unfortunately, Ayan had been denied admission at every school his mother visited. She was at a loss and quite stressed trying to find an accepting environment for him. Apparently, the schools only wanted children with disabilities who could compete with the other children.

## What is disability?

According to the *International Classification of Functioning*, disability (or health disability) is a term encompassing all impairments, activity limitations, participation restrictions, as well as environmental factors. A child born with certain limitations or some form of impairment is termed, 'disabled' - someone who is unable to function like the

majority of the population. Living with a child with disability can have a profound effect on the family and its functioning. The above snippet points out the discrimination and stigma a child with disability and his or her family have to face. While most families accept the child and the disability early on, they always have to face challenges associated with bringing up a child with disability (Bennett, Deluca & Allen, 1995). When we think of the various issues related to children with disabilities, we tend to skip the ripple effects of disability on the families. Ayan's mother, in this case, had to struggle physically as well as emotionally to cater to her child's needs.

There are several costs that the families need to meet, such as appointments with various healthcare professionals, lack of childcare services affecting the parents' ability to work, lack of effective life skill training or education etc.

According to the social model of disability, the presence of mere impairment does not make a child disabled, rather the environment has a larger role to play by creating a disability from impairment. The inability of an individual to participate in routine activities of life arises from the exchanges between the individual's body and the environment where the individual lives.

*'...I sometimes think of taking Ayan and shifting to some small town or village. People there are at least sensitive and accepting due to their ignorance or unfamiliarity. Ayan will at least have friends there. People in remote villages might label him as nasamajh (mindless) but wouldn't alienate him like the people in the cities do...'*

More children (with disabilities) are being raised at home rather than in institutional care due to the attitudinal trend of marginalisation (Appleby, 2014). Is disability a perception? How do people look at disability? Similar questions arise when we try to delve into the whole issue of disability from the perspective of a non-disabled individual. Disability usually evokes feelings of fright, curiosity, anxiety etc. Many of us are usually unsure of how to behave towards an individual with disability. Take for instance a child with visual impairment

trying to reach a certain destination. Should we act with care by helping the child or should we ignore the disability? Will an act of care be seen as demeaning? Are we marginalising the child by trying to help or by acting as if the disability doesn't exist at all? When we see a child with disability, we tend to provide assistance implying that we are superior, consequently, discriminating against the child with disability. Unintentionally, we happen to treat individuals with disability as lesser than the rest.

### **Disability and social bias**

A newborn baby is always seen as a gift of God and as a being who requires constant adult care. However, if a child is born with some visible deformity or congenital 'defect' then, he or she is not warmly welcomed or accepted by society as compared to a 'well-formed' child. Additionally, Indians believe in the theory of *karma*, that is, a child born with some form of visible impairment is said to be a consequence of the child's or its parents' wrong deeds in a previous life, leading to the stereotyping and marginalisation of the child as well as the parents. The family and the child must adapt to these circumstances and develop resilience.

One major hindrance in giving the required support is economic inability. There are several examples where one parent, mostly the mother, has had to leave her job to provide full-time care. Observing other children living differently, attending school, playing with peers, making friends can impact the child's self-esteem.

### **Disability in the context of school**

The mere act of going to school itself can develop a sense of self-esteem, confidence and well-being in the child with disability. Attending schools with other children, sitting in classrooms like everyone else, being treated as any other child in school, promotes better well-being in children with disability (Sharma & Sen 2012). We have historical evidence of special schools for children with disabilities. These children were excluded from the mainstream education although the policies believed that children with disabilities also needed to be educated and be contributing members of society. But this led to further marginalisation as they were seen as a separate category of children who are not 'normal'.

Later schemes, like the *Integrated Education for Disabled Children* (1974) and *Project Integrated*

*Education for the Disabled* (1987), tried to include children with disabilities into the mainstream. These schemes attracted a lot of children, mostly with physical rather than intellectual disability into education. In 1997, the term 'inclusive education' was included in the District Primary Education Programme. Following this, the National Policy on Education (1986), Rehabilitation Council of India Act (1992), the Persons with Disabilities (Equal Opportunities, Protection of Right and Full Participation) Act (1995) and The National Trust Act (National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability (1999) stressed upon providing supportive learning environment to children with disability. These policies, schemes and acts have been successful in enabling access to schools and creating awareness about the importance of integrating children with disability in mainstream education. With the implementation of the Right to Education Act (RTE) 2009, every child, including children with disabilities, have the right to be in schools.

How far schools have been successful in providing effective inclusive settings for the children with disabilities is still a question. Creating an inclusive learning environment for children with disabilities within mainstream schools might take a long time. Children with disabilities now have physical access to school, are exposed to formal education, but the negative social perceptions of teachers, peers, and other students still interfere with their right to education. Several disabilities, such as learning disabilities, emerge when children enter the formal set-up of a school. Children with learning or intellectual disabilities are at a higher risk of not getting proper education compared to children with physical disabilities. The lack of properly trained professionals in schools, resources and awareness about future options are a few of the reasons behind the absence of children with intellectual disabilities from schools.

When I visited the Azim Premji School, Matli in Uttarkashi, I observed Akshat,<sup>iii</sup> a nine-year-old child with Down syndrome in the LKG class. When I asked, the teacher said that it was his first time in school. He had never been to any school before that. Like Ayan, he had been denied admission by all the schools in the vicinity. The parents knew that their child was special but seemed unaware of what this entailed. His mother would ask the teacher, '*Madamji, kab padhna-likhna shuru karega ye? Kab*

*poems aur rhymes gaana shuru karega?’ (Madam, when will he begin to learn to read and write? When will he start reciting poems and singing songs?)*

It made me think that while Ayan’s parents had lost hope and were disturbed by the social stigma, Akshat’s parents, on the other hand, had positive expectations from him just like other parents. Conversations with the teacher also revealed that Akshat’s mother forced him to read and write at home. Due to her lack of awareness, she may not know how to engage academically with Akshat. But even if her expectations are unrealistic, Akshat’s mother believes he has potential. Akshat was seen playing with the young pre-schoolers, showing love and care for his friends while Ayan was mostly avoided by children. Comparing both the situations make this statement of Ayan’s mother, real:

*‘...I sometimes think of shifting to some small town or village with Ayan. People there are at least sensitive and accepting due to their ignorance or unfamiliarity...’*

In an era of rapid polarisation and rise in hate crimes there is a dire need to foster sensitivity, empathy and care for all beings from an early age. Schools can act as empowering and inclusive spaces for children with disabilities and to achieve this, children and parents need to be prepared well, but most importantly, the teachers need to be prepared. Pre-service training programmes for teachers are not effective enough to fully equip the teachers to manage children with mild or moderate disability in classrooms (Sanjeev & Kumar, 2007). Though the curriculum of such training/courses/workshops include the significance of inclusion, kinds of disability etc, they hardly cater to the social perceptions of stereotyping, stigmatisation and marginalisation of children with disabilities. It is important for the teachers to be aware of such

biases and stereotypes because the teachers’ attitudes not only affect the way the teacher teaches but can also influence the attitudes of the other students.

Schools need to build an environment that promotes resilience and develops empathy. The skills of navigating and negotiating through resources to sustain well-being (Ungar,2006), such as the ability to identify psychological, social or physical resources when needed and also, the motivation to access resources, like talking to people when sad etc., need to be nurtured. It would take a long time to make every space disabled-friendly which is how society will become inclusive but a school climate where everyone consciously listens to and understands each other’s perspectives, can be created.

Can we see disability as diversity? Does diversity only mean cultural, religious or linguistic diversity? Even though India is a proud ambassador of multiculturalism, comprising varied cultures, religions, languages, practices, ethnicities etc, there are several instances of ethnic and language conflicts and riots. The Indian Constitution recognises and protects the religious and cultural diversity. There is need to rethink the idea of diversity when we only define it in terms of cultural practices and beliefs. Diversity in all forms needs to be acknowledged. This will result in the creation of accepting, respecting and nurturing environment for every human being. We believe and appreciate that all children develop at a different pace and all children are different. Children with disabilities also develop differently, acquiring skills, communicating, functioning and growing at a different pace. A positive acceptance of children with disabilities in classrooms and schools can reduce social bias and stigma from the minds of people.

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<sup>i</sup> Name changed to protect identity.

<sup>ii</sup> A case study conducted in 2012 as part of M.Sc. in Human Development and Childhood Studies.

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