

“This is my journey.
My unique path.”

Today there are several memories coming in my mind continuously. As I go down the memory lane, a picture of an 8 year old girl flashes everytime. The story takes me 3 years back in the time line where I met this girl in Baglung district, a remote area in Mid-Western region of Nepal. After finishing the meeting, my team and I decided to visit a famous temple situated nearby. While going to the temple, we had to cross a lonely pathway in the mid of the forest area and there I saw this girl by the side of the road.

Being into this profession, I could easily recognize her as Down syndrome. I offered her to come with us to the temple. The girl happily agreed to this. But to my dismay, as soon as we reached the temple the priest shouted at her for entering the holy place. On enquiring I found that the girl did a lot of mischiefs there due to which she was abstained from entering the place. I somehow intervened and ensured that the girl would stay with me and would do no harm to the temple property.

While returning from the temple, I met the girl's mother who was coming back from the forest after gathering some leaves and twigs for her daily use. I asked her some basic questions and the answers which I received were heart reddening. Is it safe to leave your daughter alone in the forest, where is your husband, why do you leave your daughter- these were my queries. And her answers revealed a mother's tyranny. She was a single mother and her husband left her because of her daughter's intellectual disability. She lived alone with her daughter by selling flowers to the temple visitors. Every morning she would leave her daughter alone and go out to earn food. She was apprehensive about her daughter's security, feared for her sanity, but was helpless to all this as she had no other option but to leave her there.

I came back to Kathmandu but the incident could never leave my mind. An eight year old who doesn't even know the meaning of discrimination is being differentiated daily. And the person who does this injustice upon her is none other than the temple priest. Look at the irony, according to the Hindu mythology, priests are considered next to God. Can you imagine a God discriminating His worshippers? Her father left her mother because she gave birth to an intellectually disabled child. Is this the fault of the mother or the daughter that she was born like this? We are living in 21st century but are still bound with the shackles of old superstitions and illogical mindsets.

This is not just one story; you can find it in every nook and corner of Nepal. There are plethora of laws and regulations prohibiting people from committing any such crime. But the laws quietly reside in the books and a new criminal is born every other day. So who is the looser in all this? The male dominant society has carried many atrocities upon the opposite sex. Women are threatened, beaten and left all on their own. But the society keeps watching like a silent spectator.

A woman left by her husband is neglected by the society. Her daughter is her sole responsibility. She is molested, sexually harassed or even if raped; there is no one who will defend her. And just imagine a girl with intellectual disability. She is so vulnerable and an easy prey to all such harassments. She can never express her pain and her mother can never seek justice for innocent daughter. Cruelty is so much that even after all this; it is the mother and the daughter to be blamed. We have cases where a mother and her intellectually disabled prodigies took away their lives. There is no safe haven for them. She can never think of her daughter get educated. Out of the 75 districts in Nepal, none of them can claim a safe and sound learning center for intellectually disabled ones. After the onset of her menstrual cycle, girls stop going to these centers because their mothers cannot protect their daughters. Time passes by but the atrocities and injustices never end. Or maybe it keeps increasing with a new victim each day.

The crisis aggravates with the Charity based policy employed for these children. They don't need charity; it is their humanitarian right to live a life with dignity. United Nations Convention of the Persons with disabled (UNCRPD) was ratified in the year 2008. In spite of this the Charity based model has not been upgraded to the Right based approach. It is good to know that two beds are reserved in every hospital for the intellectually disabled children. But what if a disaster occurs and two more such children need the bed. Now should the other two pay for their own hospitalities? Is it correct to ask for money from them? Isn't it their right to get free medication?

We promote "Education for All" so do we have good institutes for these children? The ones running, lack proper infrastructure, good training for the teachers and the curriculum for the children. Is it fair to neglect their education or they have no right at all?

Talking about social security: Our government provides Rs. 1000 to the children who are severely disabled. But the prominent questions that are still waiting for solutions are- Is the money enough to survive? Does the money reach the needful? What if the child requires a caretaker? What if it needs expensive medication?

The parents of intellectually disabled children can never take them to public places for recreation. The government has provided them with no such facilities to do so. A small step taken by the government, for these children, remains hidden because of the lack of awareness in the society.

It has been more than 12 years since the country started working for the people with intellectual disability. But it is so sad that we are still fighting for the basic needs of these children. The country can never prosper without the prosperity of its citizens. So are these children not the part of our country or are they someone from a different planet? It is high time now and any more delay will just exacerbate the plight of the child. So better do something than wait for someone else to do it.

Families are the greatest assets of a person with intellectual disabilities. So it should be kept in mind that it is not only the child who has needs but the parents and the families too. There is a great need to focus on helping the families learn how to work with their children. Parents should be involved and encouraged in understanding their children with intellectual disabilities. Parents need continuous support and advice

because a intellectual disabled is a permanent condition . One must be sensitive to the needs of the family, have patience, listen carefully and give them realistic but hopeful information. So the researcher tried to focus the study on the families of the person with intellectual disabilities.

Emphasis need to be given to prevention. Knowledge about Intellectual disabilities should be spread among the adults who are going to be the future parents. By doing this, it will decrease the possibility of having a child with down syndrome/intellectual disabilities and will aid in the eradication of false beliefs regarding the causes of down syndrome/intellectual disabilities which possibly may crisis in the family.

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- Shila Thapa

(mother of 12-year old son with down syndrome)

- President of down syndrome society Nepal

- Programme co-ordinator of satyam day care centre

