

# Introspection of Visually Impaired Children: a Qualitative Study in a Blind School of Kolkata, West Bengal

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## Abstract:

**Introduction:** The world has 1.3 billion people living with some form of vision impairment which is associated with problems related to mobility, education, occupation and activities of daily living leading to stress, mental trauma and stigma of these children & their family members. **Objective:** Exploration of stress, stigma and mental trauma of parents of visually impaired children of a blind school, Kolkata, West Bengal. **Material & Methods:** It was a Qualitative study conducted from May to July in 2018 in the form of 5 Focus Group Discussion among parents of visually impaired children & Key Informant Interview of Principal of the Blind School. **Result:** These children, were equipped to identify presence & activity of other people by their other senses. All parents complained about bad behavior of Bus conductors & co passengers. Children had a good relationship with parents but domestic violence and divorce was also there. Sometimes children were restricted to participate in social programme in the family. Communication difficulties between parents & children was present during illness of children. Parents had stress regarding brail technique adoption by children. Principal of the school addressed some problems like suicidal tendency, depression etc. **Conclusion:** Awareness programme addressing needs, problems & support of visually impaired children should be organized in the community, Transport Division workers etc.

**Key words:** Blind, children, education, school, stress, stigma, qualitative, Visually impaired.

## Introduction

The world has 1.3 billion people living with some form of vision impairment. Among them 826 million people live with near vision impairment.<sup>1</sup> Developing countries like China and India are the countries having the maximum number of visually impaired persons as per WHO.<sup>2</sup> Prevalence of visual impairment in India is 5.3% which is almost double compared to American, European and even African countries.<sup>2</sup>

Out of India's 132 Cr population<sup>3</sup>, 2.68 Cr persons are 'disabled' which is 2.21% of the total population, out of which 19% are suffering from visual impairment.<sup>4</sup> West Bengal with its population of approx. 913 lacs, has 4.2 lacs people who are visually disabled.<sup>5</sup> Various initiatives under National Programme for Control of Blindness are targeted

towards achieving the goal of reducing the prevalence of blindness to 0.3% by the year 2020.<sup>6</sup>

Blindness is a disability which is associated with problems related to mobility, education, occupation and activities of daily living leading to stress both to the visually impaired persons and also to their family members. They are also subject to substantial stigma and discrimination leading to depression, anxiety and stress and suicidal tendency. It is very unfortunate that the blind children in their growing years have to bear the brunt of the menace of this disability, putting their normal life in jeopardy and their dream to aspire in life dashed to the ground. Despite a dearth of evidence regarding this issue, difficulty at every stage of day to day activity of the blind is expected to be more in developing countries like India

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compared to developed countries, more so among children than the adults. Assessment of stress, stigma and any such mental trauma can be best done by an introspection of this unfortunate population through a qualitative research as has been done in this study.

#### **Objective:**

This qualitative study purpose was to explore the problems & issues related to life of blind and visually impaired children causing stress, stigma and mental trauma after discussing with parents & Principal of a blind school, Kolkata, West Bengal.

#### **Materials and Methods :**

We had taken ethical approval for the study from the Ethical Committee of AIHPH and permission to conduct the study from the Principal of the Blind School. This qualitative study was based on grounded theory methodology.<sup>7</sup> The study was conducted in a government aided Blind School situated in South Kolkata having 90 visually impaired children from class 1 to class 10. There was facility for residential stay with separate hostels for girls and boys. Multiple complementary methods of data collection were used to ensure that the findings would explore both breadth and depth of information. Data collection included 5 Focus Group Discussions and one key informant (Principal of the school) interview.

Discussion guides for the FGD and interview for the key informant interview were developed from the review of literature and inputs from the experts of All India Institute of Hygiene and Public Health. All efforts were made to make these guides appropriate, robust and wholesome. It took 3 months (from May 2018 to July 2018) for the research work to be completed from its inception to its completion and report writing.

A convenient recruitment strategy was used to recruit participants for FGD. Out of the total 90 children of the school 40 students were staying in the hostel. The rest of the students were days' scholars. We conducted 5 FGDs on the mothers of the days' scholar students. Each FGD consisted of 7 to 8 mothers. Participants were contacted through the Principal of the school. Mothers of hostel students were invited to attend FGDs by letter but they could not come as all of them were from remote villages of districts of West Bengal with very poor socioeconomic status.

The standard protocol for conduction of all the FGDs was followed. In each of the FGDs after welcoming the participants, they were seated around a round table. At the very start informed written consent was taken from the participants. The moderator assured them of confidentiality regarding all information obtained from them. Two Note takers sat on either side of the moderator. An audio recorder was placed in the centre of the table for voice recording of

the whole session. The sessions were conducted by the moderator with the help of the discussion guide prepared beforehand. All efforts were made by the moderator to involve all the participants in the discussion with due encouragement for the shy participants and restriction for the loquacious ones. The note takers noted in details the verbatim records and also records of nonverbal expressions of the participants. Each FGD lasted for a period of 45 to 55 minutes. At the end of a FGD the moderator thanked the participants, offered them some refreshments and asked them if they had anything more to add to what they had already said. The 5 FGD were conducted one on each day for a period of 5 days and on the last day an in depth interview of the principal of the school was conducted.

#### **Data analysis :**

It was done through thematic analysis approach. Coding was done for similar ideas/topics and these were funneled into broader themes. The first step was writing whole extract called transcript formation. Then initial codes were generated by organizing the data into meaningful groups. Coded extracts into similar ideas were funneled into relevant themes. Reviewing of participants' quotes were also done and finally, connections among various quotes and codes were made to produce the final themes with names. The final theme names were then developed through collaborative discussions among the researchers.

#### **Results:**

##### **Problems and issues stated by the parents:**

##### **1. Mental and Emotional Status of Children:**

Some mothers stated that their children were very obstinate with frequent outburst of anger. On the other hand, their intelligence and memory level were very high. These children also had the habit of asking too many questions to their parents. They could easily identify the owner of any voice they heard. They also had the special ability to recognize known people with the sound of their footsteps or through their body odour or by feeling their dress or body. Only one said that her child whom she had adopted at the age of 2 months had a chronological age of 7 years but her intelligence was akin to a 5-year child. This special child had undergone 3 years special training for speech and mental development in a National level training institute in Kolkata. There were very few children who were soft and calm by nature.

**Quote 1:** 'My child is very adamant, cries for things, throws things, it's very difficult to control her anger.'

**Quote 2:** My child can memorize very fast by listening only and can identify persons by their voice, sound of feet, smell of body etc'.

##### **2. Travails of Travel :**

Nobody used dog or cane while moving around both within and outside their house. When travelling outdoor they were

always guided by someone who could see. Many of the mothers claimed that their children could identify the bus/auto stoppage and had no difficulty in plying to and fro by public transport.. Most of the mothers were terrified to let their child travel on their own.

All the mothers opined that their children faced major stigma while travelling in the bus. The co passengers and the conductors were not at all sympathetic towards them. The mothers claimed that they were often intercepted while these children were talking or discussing or asking questions while travelling.

**Quote 3.** 'I am scared to let my child travel on his own. Bus conductors, drivers and co passengers misbehave with my child. Handicap card is often demanded by drivers before boarding a bus though the disability of the child can easily be witnessed'.

**Quote 4.** 'Sometimes when he talks excessively the crowd in the bus gets irritated.'

### **3. Life with Family :**

There was no stigma or problem as such within the family. Their normal siblings were very understanding with whom they had very good relationship. The protective mothers took a lot of care of their children in social gatherings so that the children hardly had to face any adversity for their disability. However, the mothers claimed that there was always a lingering cause of stress among the parents for their disabled children. One mother expressed her sorrow for being unable to exactly describe the beauty around her to her child when she watched beautiful things in social gathering like sari, jewelries etc. Many mothers claimed that in social functions their children talked a lot or asked plenty of questions which irritated those who were around them. However, few mothers said that their children often did not open up when they were sick.

**Quote 5.** 'My child talks a lot in social gathering which other people sometimes dislike.'

**Quote 6.** " My child never speaks up when he is sick'

### **4. Issues related to education and future life :**

Regarding the education of their special children, most of the mothers were stressed due to difficulties faced by their children during brail technique learning especially for mathematical calculations. Regarding marriage, most of them had not planned anything beforehand & said that their children would decide about their life partner when they grew up. Almost all the mothers were very worried about the financial independence of their children once they grew up

**Quote 7.** 'I feel mathematics in brail to be toughest to learn'

**Quote 8.** 'I want to keep money for them in future. I wonder if my child will ever be able to stand on her own feet.

**Quote 9.** 'There is no science department in the blind school so the child has to take arts subject and so I feel that there is

very few scope of a job for him in the future'.

### **In depth interview of the principal :**

#### **1. Life in School :**

The principal was herself visually impaired, she could understand the plight of her students more intensely. She seemed to be very empathetic towards the suffering of the students and was doing her best to ameliorate their affliction with care, compassion and affection.

#### **2. Facilities Available in School :**

The children of the school were very friendly among themselves; as a result they were very much at ease when they spent their time with their peer group. Studying in a special school deprived them to mix or interact with normal children though their intelligence was at par with normal children.. There was a big play ground and there was facility for both indoor (chess) and outdoor games (football, cricket). Music and Arts subjects were taught in the school with no place for science subjects in the curriculum.

#### **3. Dream Projects :**

She talked about her dream projects for the welfare of her dear students. She planned to introduce Computer Course, Spoken English course, Brail library, government recognition for vocational training course of blind students and hold regular cultural Programmes to improve mental and social health of students. She also had plans to turn the school into a barrier free building.

#### **4. Impediments for Growth :**

Most of the students were from very low socio-economic strata of the community and many were even below the poverty line. The aid obtained from the government was insufficient and therefore she had to depend on corporate and other donations for survival, which again were inadequate, irregular and infrequent.

#### **5. Poor mental health :**

According to the principal poor mental health of the students is a matter of concern since she had detected some of these students suffering from depression, with suicidal tendency. She had planned going to take the help of a counsellor for this.. Measures to avoid suicides had been taken like mandatory twin sharing of rooms and instructions to parents to not to give knife, scissors, blade to their children.

#### **6. Adverse attitude of Parents :**

Sometimes parents detained their children in the school only because they did not want to take them to any social gathering or function. This might be very convenient for the parents but this act of dumping their children in the school and deterring them from participating in family or social functions led to mental trauma and turmoil among them. They felt left out & burden to their parents and that they were being deprived of their opportunity to mingle with normal people.

## 7. Problems related to Hostel :

She stated that funding for their hostel was very less from government and it needed renovation. Provision of nutritious diet for hostel students was becoming difficult as their pond in hostel grounds was not being utilized for fish farming. This financial crunch reflected in the poor manpower and unhygienic premises of hostel.

### Case Studies :

1. A mother had adopted a child whom she found abandoned near a public vat. Obviously this baby had been dumped by her parents because she was blind. However, the mother who had adopted her gave her all the love, care and affection as much, may be more than her biological mother.

**Quote 10.** 'When I found my special child first she was 2 months old and lying in the roadside as she was thrown away by her family due to her blindness at birth.'

2. Domestic violence in family was affecting a 6-year-old male child, making the child adamant and unruly. The child disliked his father who beat his wife regularly. The mother complained that the child was neglected and was almost hated by his father; his only fault was his visual impairment. The father implicated the mother for the child's disability resulting in domestic violence and extramarital relationship. Recently he divorced his wife and now the mother was a single mother.

**Quote 11 :** 'A 6-year boy is very adamant and unruly and beats his classmates. From the family history I found that in his home, his mother was beaten by his father regularly. Ultimately his father divorced his mother and remarried.' (Principal's statement)'

3. The elder child of one participant, a working girl has given up her plan to marry since she felt that once she would get married, her in laws would not allow her to support her family.

**Quote 12:** 'My late husband had very good bonding with his two daughters. Now my elder normal daughter is doing a job after completing her studies and supports us both financially and mentally. She refuses to marry anyone who will not accept her visually impaired sister's responsibility.'

### Discussion :

The themes generated in this study were issues of visually impaired children related to emotional status, mobility, family life, education and future. Principal of the school stated pertinent issues regarding the welfare of the students who faced social stigma at every stage of life. Our study reflected the familial deprivation of visually impaired children in respect to education, entertainment, socialization. Marginalization and discrimination by the society were present since they were born. Our study detected the different grave mental issues related to visual impairment like depression, suicide etc. In a study, V. Tadić et

al.<sup>8</sup> identified similar themes like social relationships, participation and acceptance, independence and autonomy, psychological and emotional well-being, aspirations and concerns about the future and functioning at home and school. Kurtović A et al.<sup>9</sup> showed that depression among visually impaired people was negatively related to the level of education, optimism, self-liking, self-competence, support from friends, family and coworkers. He also showed that depression was positively related with comorbidity and pessimism. Ellen B.M. et al.<sup>10</sup> in a study showed that sports camps, prescription and training in the use of low vision devices, might be effective in improved functioning of visually impaired children. In our study, the principal of the school also tried to improve mental health of the students by organizing sports, music, social and cultural Programmes. P. martin et al.<sup>11</sup> in a study documented that visually impaired people showed a strong decline of vision-specific psychological well-being with time which was supportive to our study findings. Lupón M et al.<sup>12</sup> found that caring a visually impaired child was influenced by psychosocial factors and information and guidance to understand the child's visual condition. The latter was found to be quite insufficient. In a dissertation work, Z.Xiaofang<sup>13</sup> found that some blind students used guide dogs and blind canes without difficulties. But in our study no body used these helps. In the above mentioned study, some students had difficulties in learning Brail technique which finding was similar to our study. Blind students in that study faced difficulties in public bus and train regarding exact location for destination as no notification or alarm was not provided. Similarly in our study parents along with their blind children faced misbehavior of the bus driver & conductor. Regarding study difficulties both our study and the aforesaid study got the same findings stating mathematics was most difficult to learn by them. In that study, government provided long canes, guide dogs, braille books, computer, training on orientation and mobility. But in our study we found poor financial condition of the school affecting nutrition and boarding of students badly.

### Conclusion:

As per WHO's action plan 2014-2019 on universal eye health<sup>14</sup> focusing on the principle of rehabilitation of visually impaired persons our study may help in providing guidelines and policy formulation by our government for effective, feasible and appropriate measures to ameliorate the suffering of this marginalized, unfortunate and ill-fated section of the community. Regular awareness Programmes should be there at the level of the family, community, school and transport department to deal with this population with compassion, kindness and sympathy. Disability specific relief measures like popularizing brail books, brail library, computer training with whole hearted government support will deliver hope, happiness and health to the blind. Contribution and

participation in this noble work by the NGOs and the corporate sector through Corporate Social Responsibility (CSR) will help the blind & visually impaired people to join successfully the journey of the mainstream of the society. This goes in line with what Mark Twain said "Kindness is the language which the blind can see".

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