



## **Lived Experiences of Children with Disabilities: Some Case Studies from Aizawl, Mizoram**

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### **Abstract**

*Persons with disabilities are likely to suffer from stigmatization, discrimination and exclusion in society because of their impairment and their handicap. As stated by Oliver (1996), “disabled people have been mistreated, abused, and disadvantaged on many fronts”. They have little place in society as a result of their challenges. Children with Disabilities (CwDs) are among the most vulnerable group in society. Their vulnerability can have three aspects that include age, gender and their disability. As a result of this, they are subjected to abuse in all forms. CwDs have little voice and remain hidden under the carpet. They are likely to belong to poor family and require a lot of support including financial and material assistance for their wellbeing. They are also less likely to be enrolled in schools and are more likely to have poor academic performances. This paper shall delve into the lived experience of CwDs highlighted through several case studies of CwDs in Aizawl, Mizoram.*

**Keywords:** *Children with Disabilities, Disability, Challenges, Support.*

### **Introduction**

Children with Disabilities (CwDs) are among the most marginalized and excluded groups of the society whose voices were hardly heard. They experience certain violation of rights and encounter certain kind's discrimination and exclusion (UNICEF, 2006). As seen in the World Report on Disability (2011), approximately one billion people in the world are living with disability where at least 1 in 10 are children. It is estimated that a number of children between 93 million and 150 million children are living with one or other disabilities where 90 per cent of Children with Disabilities in the world do not attend school to receive education. According to Childline (2010), it is noted that 1.67 per cent of the 0-19 population are living with one or more disability in India, out of which 35.29 per cent of them are children. In India, a total number of 12 million Children are estimated to be living with

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Disabilities in India. Out of these, only 1 per cent of children with disabilities have access to school. It is also noted that one third of most disabilities could be prevented. In 2016, the Rights of the Persons with Disabilities act were enacted in order to promote and protects the rights and dignity of PwDs in India.

In Mizoram, the Department of Social Welfare is responsible for the welfare of Persons with Disabilities. The state has little statistical data of CwDs, but from Census (2011), the state has an estimated population of 15,160 persons out of which 3,748 belong to the age group 0-19. According to the Rights of Persons with Disabilities Act, 2016, “person with disability means a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others”.

According to Article 1 of the Convention on the Rights of Persons with Disabilities, the term, ‘children with disabilities’ is used to refer all children up to the age of 18 years who have ‘long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.

### **Overview of Literature**

Children with Disabilities (CwDs) are likely to belong to low income family (Mohisini & Gandhi 1982; Filmer, 2008; Tran, 2014). CwDs are more likely to live in a broken family with a single parent (Cohen & Prahova, 2006). People of ages 6-17 are extensively less likely to start school and are less likely to be enrolled in schools (Filmer, 2008). There is lack of trained teacher in educational settings and lack of infrastructures in school settings (Tran, 2014). There is also lack of awareness of different schemes which then results in the underutilization of services and schemes (Mohisini & Gandhi 1982; Soorenian 2013; Tran, 2014). There is also lack of social assistance to CwDs (Desai, 1990; Tran, 2014). There also exist different different barriers to accessing the different services for CwDs (Klassing, 2007).

There is existence of social stigma and discrimination that excludes CwDs from their peers (Ali et. al, 2001; Mishra & Gupta, 2006; Cardona, 2013; Sylvestera et. al 2014; Goodley & Runswick, 2015). It is also found that children with disabilities encounter various forms of abuse by the teachers in the special education schools (Shumbaa and Abosib, 2011). Because of certain exclusion, CwDs prefer to interact with those children with disability than those children who are not so handicapped (Harper and Wecker, 1989). Disability’ does leave emotional scars and a feeling of dependence and helplessness (Singh and Ghai, 2009). The deprived handicapped children are likely to have a feeling of inferiority and depression (Bhatia M. S., 2009). CwDs are more like to adopt behavior problems and also that Children with disabilities have a lower level of social competence on the average than community children (Varni & Wallander, 1989).

## **Methodology**

The Study was exploratory in design and was conducted within Aizawl City. Data were collected from primary source that include Children with Disability and their care givers. A purposive sampling procedure was utilized. Children were identified from Institutional and Non-Institutional settings working for children with disabilities in Aizawl. The study utilized case study as a method for data collection. Nine case studies were conducted among CwDs in Aizawl City. Only those children who have consented were included in the study.

## **Results and Findings**

### ***Case 1***

A 17 year old, *Zovi* (fictitious) was born a normal baby to a poor Christian family and belongs to Presbyterian denomination. Her mother was diagnosed with Tuberculosis and was often being physically abused by her father who was an alcoholic. When she was six years, *Zovi* suffered from severe cough and was given treatment for tuberculosis though it was never confirmed she had tuberculosis. She was often abused physically and verbally by her father. During her early childhood, she showed developmental delays and later she was diagnosed with intellectual disability. Her parents got divorced in 2004. Since her mother did not have anyone to rely upon, she went to a Home where both of them were admitted. Her mother died in 2007. Her father also died soon after her mother's death.

After the death of her parents, she remained in the Home where she received education. She has poor academic performance and because of her unsettling behavior in school, she could not continue her education. *Zovi* was once taken for foster care but could not stay long because of her anti-social behavior. She was truant and would leave the Home without permission. She was then admitted to a different Home for Children with intellectual disability.

She loves to play with friends but since she has attachment problems, she cannot be in the company of the same person for a long time. She has mood swings and often laughs out and cries suddenly for no reasons and frequently shows rebellious behavior by damaging objects. She often play 'dead' and also often injures herself. In spite of her behavior, she loves to draw and colour pictures and also knits well. She is also very responsible and has the potential to carry out duties that falls on her hand. Though it was difficult to perform therapeutic session with her, with certain psychological and medical treatment and counseling, *Zovi* slowly learnt positive behavior and started to overcome her anti-social behaviors. From her behavior and character, it was not at her best interest to continue studies, so the home will be finding measures for life skill training so that she will be able to acquire skill according to her capacity for her sustenance in future.

### ***Case 2***

*Zuala* (fictitious) is an 11 year old boy who was born to a poor family suffering from intellectual disability. *Zuala* too, was diagnosed with mild intellectual disability. He is a Christian and belongs to the Presbyterian denomination. He has developmental delays which

include development delay in speaking, learning and behavior. After the death of his father, his mother remarried to a differently abled beggar in Myanmar and as a result of this, *Zuala* and his two brothers had to stay in a children's home. And since he has a special case of disability, he could not stay with his brothers and was shifted to another home for the intellectual disabled. *Zuala* was given formal school education by the home and studied till class IV. He has poor academic performance and got promoted to higher classes according to his age and not according to his merit. Because of his disability, he could not continue his education. His mother never visited him or his brothers during their stay. The home had no records of his immediate relatives for reintegration. In order to bind the bond with his siblings who were staying in another home, plans were made by the home and certain measures were undertaken for them to stay in touch.

*Zuala* is very active and creative, but has great mood swings and often quarrel and fight with his friends. Measures were taken to modify his behavior which includes behavior modification therapy, medications, counseling and education from a special educator. Though certain measures have been taken for his behavior modification, he was not very cooperative and attentive especially during counseling. He often sits inappropriately and smiles, shout or laugh out loud with no reasons. *Zuala* mentions how much he misses his mother and his two brothers.

### **Case 3**

*Sangi* (fictitious) is a 16-year-old girl who was born from a very poor family. Their family migrated from a rural area to Aizawl to have a better living. Her father is an alcoholic and was often violent towards the family which made their situation more miserable. Her parents got divorced in 2013. *Sangi's* disability was identified after she suffered from a severe ear infection when she was just 3 years old. She received medical treatment, but due to financial problem, they could not afford better treatment and her ear was left untreated which caused a serious infection, and because of this her sense of hearing became impaired.

*Sangi* studied till class IX, but dropped out from school due to her hearing difficulties in class lectures and the discrimination she experienced. Her impairments affected her psychosocially and she became reluctant to socialize and chose to be in isolation from peers. After dropping out from school, she started working in a tea stall. But since she had difficulty in communication, she could not continue the work. In 2015, when her mother got remarried, she stayed with one of the family in their locality and helped them with household work. For few months, she was paid for the work, but later the family chose to take her into the family and provided her with all the necessities in life. With the help of the family, she received treatment for her ear and even got registered in one society for differently abled where she received hearing aids. The family even bought a kit for improving her hearing. She was taken for medical checkups and treatments regularly. And with all the measures taken by the family, she showed great improvement in her speech and hearing. At present, *Sangi* attends a tailoring class at a private institution.

Although she received enormous care from the family, she finds it difficult to adjust herself with the new environment and misses her mother. Even though she received love and care, the father of the family who was an alcoholic sometimes verbally abused her. As Sangi said, 'When I could not hear his calls or hear what he says, he shouts at me, derogatively'. Such kind of experience makes her feel very uncomfortable and uneasy.

#### **Case 4**

An 11 year old *Dina* (fictitious) was born a healthy baby. By the time he was two years and six months, he suffered from conjunctivitis, which eventually cause his visual impairment. *Dina* is Christian by faith and belongs to Presbyterian denomination. Because of his disability and health problem which require expensive treatments and medication, he stayed with his grandparents. By the time he was 4 years old, his grandparents admitted him to a Special School. And when his parents heard about it, they were really disappointed and immediately took him out of the school so that he would not be stigmatized and discriminated as a disabled. But after his grandparents told his parents about the benefits of sending him to school, he was again admitted to the Special School. *Dina* has great potentials in studies and obtains first position in most of the examinations. The school even provided him with the study materials that he need including stylus slate and blind stick.

He is a friend-loving person, loves to be around peers, and greatly misses his hometown. During long vacations, he goes back to his home town which was always the best time for him. He even said that he use to collect vegetables from the farms and could even differentiate the vegetables by touching. Loneliness is one of his main challenge and to cope with it, he listens to radio and also watches Television.

Being visually impaired from childhood, *Dina* encountered problems and experienced certain stigmatization and exclusion especially from little children that includes unfavorable comments and teasing. When such were reported, the parents of the children who teased *Dina* never gave any importance and sometimes, they even got disappointed instead. His blindness did not hinder his mobility, because he has a unique ability and skill where he uses memory and sounds made with his lips.

#### **Case 5**

*Chhani* (fictitious), aged 13, was born a normal baby and belongs to a Presbyterian Christian denomination. Her parents divorced not long after her birth, after which she stayed with her fraternal grandparents. She suffered from fever in 2012 and was in a state of coma for one month. Her illness caused her to become visually impaired. Her grandparents took different measures to cure her eyesight and searched for an eye donor. They even found one but when the doctor examined her for eye transplant, they came to realize that it was not the eye that was affected but it was the nerve that caused her impairment.

After her blindness, she could not continue her studies and was admitted to a special school where she learnt how to read and write brail. From 2014, she continued her education in the special school. Being blind, she could no longer play with her peers or hang around

with them. She no longer feels comfortable to be with them because she could not go wherever she wanted and needed to depend on her them. She was often discriminated and excluded by her peers and even by her cousins whom she lived with. All these greatly affected her mental health and often she hurt herself and even had suicidal ideation.

*Chhani* feels that some teachers lack the skills in taking care of disabled children. She also adds that she love to have normal friends but prefer those with disability. She also mentions that she wished to see a psychiatrist as she believe that it would help her overcome her miserable life. She also listens to music to cope with her problems. Regarding services, she is aware of the 3% seat reservation for disabled in government jobs and apart from this, she is not aware of any schemes and programmes for disabled especially children.

### **Case 6**

*Vana* (fictitious), who is currently 17 years old, belongs to a normal middle class Christian family. He was born without a left arm. He received normal education and now, he is presently reading in class XII. He often experience people's stare and gazes and often hears children's unfavourable comments about his physical appearance. This sometimes made him uncomfortable but he often neglected it. He was often exempted from doing work like cleaning, carrying benches, etc in schools. *Vana* use to play football during his childhood but now, he really loves to play music and performs in a local band as a drummer. He also love to ride a scooter but when he rides a scooter, people often stare at him and say, "See, a boy with only one hand is driving" and when people leave strange comments about him, he tends to have an uncomfortable feeling. *Vana* was registered in one of the non-governmental organization that works with disability and here, he received an artificial arm. But this artificial arm was too heavy and too stiff that he could not make use of it.

### **Case 7**

A 12 year old *Mawia* was born to a middle class Christian family. Not a single sign of disability was seen during his early childhood. When he was admitted in school for the first time, he lacked far behind his classmates in his academic performances. His parents eventually took him to a psychiatrist and he was diagnosed as having intellectual disability. The psychiatrist advised his parents to send him to a special school but his parents were hesitant at first since they could not accept their child's disability.

After his parents received counseling and gained awareness on the importance of early intervention, he was admitted to a special school where he received education from a trained teacher. At first, *Mawia* did not like the school because he was new to it. Besides, he had no friends. He, however, gradually adapted to the new environment and made new friends and was really attached to his class teacher. Since he was so attached to his class teacher, he did not want to shift his class even after completing his course. Now he is presently in pre-vocational class and he seems to really love the school. *Mawia* also received educational kit from the school. *Mawia* really loves to play basketball and often play along with his friends and prefersto play with smaller children. Though his parents were also aware



about the aids and services available in SCERT and SSA, they did not apply for it since they did not know the process of applying.

### **Case 8**

*Mami* (fictitious) is a 14 years old girl, who lives with her mother and her three siblings. She is the youngest child of the family. Her father passed away in 2008. At birth, her disability was not identified but when she was 3 months old, she was diagnosed as having a locomotor disability and suffers from convulsion. Her mother assumed that it must have been because of the strong medicines she took during pregnancy. She was treated with medicine in order to prevent the severity of the problem. She received good treatment from the hospital right from her diagnosis. *Mami* could function normally in the family and do the household chores in spite of her disability. She is the main person who receives guests and relatives who visited them. She is a very optimistic person and has a friendly personality.

*Mami* goes to school and do not face any problems in her studies except that sometimes she experiences convulsion. In spite of her jovial character, she often experiences stigmatization, discrimination and exclusion by other students. This causes her great distress and low self-esteem. She never complains about these incidents to her teachers due to fear of being bullied further. Apart from school, in other places people stare at her and this makes her feel different, awkward and shy. However, *Mami* does not experience any kind of discrimination and stigma in her locality. She is registered in a non-governmental organization that works with disability and received material aid from the organisation. *Mami* also receives financial aid from the church on a Sunday observed for persons with disabilities every year. Though these benefits are given to her, the family including *Mami* is not aware of any services available for Children with Disabilities or Person with Disabilities.

### **Case 9**

*Duhzuala* (fictitious), an 11 year old boy, was born a normal baby with good health until he suffered from a severe ear infection when he was 2 years old. He was immediately referred to Guwahati but since his parents did not have enough money, they could not go for further treatment. Because of this, his ear became infected that caused the eventual impairment. He was admitted to a special school in 2005. He loves to play with friends but he was often discriminated and there were many times when he went home sad since no one wants to play with him. In order to motivate him, he was sent to a badminton class but he could not continue because there was great problem in communication with his coach.

*Duhzuala* is a very bright student and loves to play computer games. He is very good in mathematics but faced difficulties in learning other subjects. He even helps his family by doing household chores.

### **Analysis of the Cases**

From the above cases, it can be seen that poverty is one of the main cause of disability since in many of the cases, early interventions and treatments could not be done due to financial problem. The cases also show that CwDs are likely to belong to broken families

who do not have anyone to rely on. And because of this, they are more liable to be placed in children homes. Further, the case studies show that children because of their disability often acquire anti-social behavior. They often have attachment problem and encounter difficulty in adapting to new environment. The study clearly shows that therapies and counseling helps the children to a great deal.

From the cases, we also see that CwDs who have high potential in learning, while most of the CwDs tends to have poor academic performances and lack behind their peers which often leads to school dropouts. We can also see that CwDs are being stigmatized, discriminated and excluded in society especially by peers and small children. They are often seen as different and encounter people's stares and gazes. We also see that CwDs are often abused physically and verbally which shows their vulnerability to abuse. The cases also highlight that parents find it difficult to accept their child's disability.

It is clear from the study that CwDs because of their disability have high dependency on others. CwDs have low esteem and uncomfortable feeling about themselves which makes them feel isolated from others. All the experiences that the CwDs encounter in life also leave emotional scars in them. They prefer to be friend with those children who have the same disability. Since friends excluded them, they often feel lonely. It can also be known from the study that in spite of certain limitations and challenges in life, they have great potential in one way or the other in order to live a happy and normal life. The study also show how different kinds of support help in the upliftment of CwDs. And though different schemes and programmes were formulated for CwDs, there is lack of awareness and information on the schemes and programmes for CwDs.

## **Conclusion**

From the findings, it can be known that financial problem is one of the main problem encountered by CwDs, it is necessary to take measures for families of CwDs. It is also very important to take measures for early identification and intervention programmes in order to prevent further disability. Counseling and therapy centers for CwDs must also be established so that CwDs could seek help from it. In most of the cases, CwDs have poor academic performances. Therefore, measures must be taken to recruit trained teachers in schools and institutions so that CwDs will be able to receive better education and prevent school dropout. This will also help the CwDs acquire higher educational status, which will increase the scope for availing the 3% job reservation for Person with Disabilities in any job settings.

More awareness and workshops on children and disability must be made so as to make the care givers aware of how to look after their disabled child. And also awareness should be made among school going children so as to eliminate discrimination and exclusion in schools. Community as a whole must also be made aware about children and disability in order to eliminate stigmatization and discrimination in communities across Aizawl, Mizoram. The study also shows that there is lack of information about the services and programmes for CwDs. As such measures must be taken so that CwDs would receive better information on the schemes and programs available for them. When there is better information on services



and schemes, there will be better utilization of the schemes and programmes which would empower CwDs in Aizawl, Mizoram.

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