

LIFE HISTORY OF BIDHAN CHANDRA SHAHA

Shree Q2 Research on Extreme Poverty in Bangladesh					
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Institution	ADD				
Household ID					
Interviewee name	Bidhan Chandra Shaha	Sex	Male	Age	37
Ethnic group and religion	Hindu				
Livelihood before the intervention	Unemployed due to disability (previously worked as a barber)				
Well-being Status before the intervention	Destitute (1)				
Marital status, children and other household members	Unmarried, lives with his parents, brother, sister, brother in law and nephew				
Union, upazilla and zilla	Shahjahanpur, Dhaka				
Dates of Interview	21 st March 2012, 22 nd March 2012				
Keywords	Destitution, Begging, Child Labour, Disability, liabilities, social exclusion, illness, abandonment, natural disaster,				

INTRODUCTION

Bidhan (37) was born in Bhola, one of the largest coastal districts of Bangladesh. His father was a barber and he used to work in a privately owned hair salon as a worker. Bidhan has a family of seven members. His father inherited a few decimals of land which disappeared from river erosion before his birth. They built a hut in their village on some land they were given as charity from a local elite person who said they could live there as long as they wanted and they did not need to pay anything to the landowner in return.

Since birth, Bidhan hasn't known what happiness was. He has never able to eat enough to have a full stomach growing up and couldn't complete his primary education since his father was not able to bear the educational expenses for all his siblings. Bidhan started to work at an early age as a trainee to learn his family business.

The cyclone of 1988 wiped out everything the family owned and they became homeless. They were forced to leave their village in search of a better life and went to Dhaka. However Bidan's experience in Dhaka was worse than in his own village. At the age of 18, before he could earn his own living and contribute to his family, he began to develop a physical problem which he could not identify the cause of. As the problem increased it was diagnosed as the GBS virus and gradually he became paralysed. He became fully dependent on the help of others, his family had to work more and his mother started to beg to meet food and treatment costs for him. Days with two meals or less became regular in his daily life.

WELL-BEING JUST BEFORE THE SHIREE INTERVENTION

Prior to involvement with the shiree programme in April 2011 Bidhan's wellbeing was as followed:

Indicator	Just before the intervention
Well-being category	1
Diets	Usually one or two meals a day though sometimes nothing
Livelihoods now - in terms of contribution to that years' income	<u>Bidhan</u> Unemployed, depends on the help of others but not a typical beggar
For other principal adult member	Bidhan's Family Members: <u>Bidhan's Father</u> Works as a barber but not everyday because he is too old (75) <u>Bidhan's Mother</u> Housewife but begs for her son's food and treatment. She is also the main carer of Bidhan which limits her earning ability. <u>Bidhan's Elder Brother</u>

	<p>barber</p> <p><u>Bidhan's Sister</u> Garments worker</p> <p><u>Bidhan's Brother-in-Law</u> Barber</p> <p><u>Bidhan's Nephew</u> Reads in a high school in grade VIII</p>
Productive assets now rank them in terms of value (e.g. land, livestock, rickshaws),	n/a
House and homestead: ownership, condition of tenure, condition of house.	<p>Bidhan Lives in a rented room (2500tk/month) which is situated in a slum like condition but is not typically a slum in nature. It is rented by his sister/brother-in-law. The six of them live in this single tin shed room. During the rainy season rain enters through the leakage of the tins and it becomes flooded. His elder brother often sleeps in the barber shop.</p>

LIFE HISTORY NARRATIVE

CHILDHOOD AND YOUTH (1975-1995)

River erosion (1973) and loss of lands

Bidhan is the third child from a Hindu family. His father was a barber in their village and was their only income earner. Bidhan's father inherited a few decimal of land which was their homestead where they had a straw house, homestead gardening and poultry. This was all destroyed by river erosion in 1973, before Bidhan's birth, and the household subsequently lived in a hut built on the land of a wealthy elite of the village. This land was offered to them because the man had had seen their terrible condition after the river erosion. In return they didn't need to pay anything to the land owner.

Bidhan's father was working as a paid barber in a hair salon which was owned by another someone else. Working as a barber was their family tradition. He kept 50% of the money he

earned during the day and the owner kept the other 50% since it was his salon. When Bidhan was born, his father had an income of 25/30 taka each day on which they had to survive and there was no other alternative income source. Bidhan's father had no capital and was unable to invest in his own shop. They were therefore only able to have food like panta/rice with cheap vegetables, potato mash (*alu vorta*) and arum (*kochu*). His mother often went out in search of the naturally available vegetables like arum and other leafy vegetables to reduce the cost of buying food. They could hardly afford meat but they could eat fish, mainly the small mola fishes, once or twice a month. Since it was a riverside area fish were comparatively cheap. They could eat egg once or twice a month but usually they had to share one egg among two or three members.

Drop out from school

Bidhan's elder sister was married at the early age of 14 because getting a daughter married at a young age requires no or less dowry. Though Bidhan was admitted to school he couldn't finish primary schooling and none of his siblings were able to either. There were many reasons behind the dropout. Despite the fact that primary education was free, his father was not able to meet the cost of exam fees, uniforms, pens and paper. His parents also used to believe that education was not for poor people like them. They thought that no matter how educated their children became they would not get any good jobs, or have the money to pay a bribe for a job. Also all of their past family members (grandfather, great grandfather) were barbers (*napit*) and this was therefore seen as the family profession, and to be a barber one needs no education.

Child labour

Having dropped out of school at the age of 10, Bidhan's father placed him and his elder brother in a salon situated in the village market as a trainee to gain the skills of hairdressing since the profession needs years of training. The salon was owned by another person and Bidhan and his brother didn't get paid for their work. They only received food and some occasional pocket money of not more than 5 taka once a month or every alternative month. Bidhan never liked it there because the salon owner's behaviour was not good. He didn't pay but treated him and his brother as slaves and used to slap/beat them for simple mistakes. He had no option but to stay because he had to learn the skills of hairdressing and there were few salons in their village.

Box 1: Cycle of Degradation

Every child is born with a possibility. Even the extreme poor have the right to dream of a life which is better than their ancestors' or different from the misery they face every day. However the reality is that if one's family business is sweeping or if someone is a cobbler or a

barber, the young children of that family will see themselves growing up doing the same profession.

The children of these families inherit a future and the cycle of poverty continues generation after generation. Each generation also inherit an identity that exists within systems of social prejudices and discrimination and therefore often cannot dare to dream beyond these. At the same time it is also usual that people wish to carry on their family profession and protect and preserve their family heritage.

Cyclone, Homelessness and migration to Dhaka

In 1988, Bidhan's family's condition deteriorated dramatically when a cyclone destroyed their home and possessions. No one in their village showed mercy and helped them and life became too hard for them to live there. Bidan's father decided they should move to Dhaka as he heard the salon business was very profitable there. They knew that many people from their village changed their a lot after going to Dhaka and they said there were many job opportunities there. Bidhan was only 13 when they moved. All of the family took shelter in a rented room in Vasantek slum and his father started working as a roadside barber in open places. Bidhan and his brother also started working in a salon again as trainees but they were not able to add to the family income as they only got food in return for their work. Their condition didn't improve that much and life went on at the same pace until Bidhan and his brother started earning independently.

It was 1992 at the age of 17 when Bidhan started working as a paid barber in a hair salon. This meant there were three earning members in the family including his father, elder brother and himself. The monthly income of the family rose from 1500 to 3500 at that time. For the first time Bidhan and his family could eat three meals a day with an increase frequency of egg, fish, and meat. They used to have egg and fish every week and meat twice a month, but unfortunately this didn't last for a long time.

EARLY MARRIED LIFE AND EARLY ADULthood (1996-2012)

Illness led to disability

In 1997, at the age of 21, Bidhan felt that his body was becoming weaker day by day. He got a strong fever one day. When he recovered from the fever he found the lower half of his body was not responding properly. People were saying that might be either rheumatic fever or paralysis. However Bidhan could still work despite his partial disability. He went to a faith healer and brought enchanted water and oil for 100 taka with the hope of getting cured. He thought he could be cured since the disability was mild at that time, but nothing worked and he continued getting weaker. He therefore went to the Dhaka Medical College for better

treatment. Doctors there couldn't diagnose his problem but prescribed some medicine. None of the medicines were available in the hospital, and although he could buy a few of the medicines it was not possible to complete the full course. Bidhan believes if he could have completed a full course of the treatment the severity of the disability might have reduced and at least he would have retained the ability to move by himself.

His father's income also shrank at that time since he was growing older and he moved back to their village and tried to earn by going to people's house to work as a barber. Bidhan could not work every day due to his illness. If he worked for one day he needed to take rest for the next one or two days. His medicine costs were at least 1000 taka per month and by then his elder brother had got married and was also not able to contribute. Gradually their situation deteriorated further making them working extreme poor. In 2003 Bidhan's condition deteriorated to such a stage that he had to use a wheel chair and he has been dependent on it ever since. In 2005 his problem got diagnosed by doctors at Dhaka Medical Hospital who said he had acute Guillain-Barré Syndrome (GBS). This caused the lower part of the body to become fully paralysed and the doctor said he would need regular physiotherapy for at least two years which would cost four to five lac¹ taka per year.

Box 1: Guillain-Barré Syndrome (GBS)²

Guillain Barre Syndrome is a rare and severe disease. It occurs after an acute infectious procedure. Guillain Barre Syndrome initially affects the peripheral nervous system. Normally it is acute form of paralysis in the lower body area that moves towards upper limbs and the face. Gradually patients lose all their reflexes and goes through a complete body paralysis. Guillain Barre Syndrome is a life threatening disorder and needs timely treatment and supportive care. Unfortunately many people lose their lives without proper and prompt medical treatment. No one yet knows why Guillain-Barré strikes some people and not others or what sets the disease in motion. What scientists do know is that the body's immune system begins to attack the body itself, causing what is known as an autoimmune disease. However, 60% of cases do not have a known cause. Some cases may be triggered by the influenza virus, or by an immune reaction to the influenza virus. There was increased incidence of Guillain-Barré syndrome following influenza immunization during the 1976-1977 swine flu pandemic. At the moment there is no effective cure for Guillain Barre Syndrome though there are many possible medical procedures to diagnose it that may help in reducing the fatal aspect of this severe disease.

¹ One lac is 100,000 taka.

² Source: www.nih.gov, www.guillainbarresyndrome.net, <http://en.wikipedia.org>

Disability leads to isolation and dependency

Bidhan started to live on the mercy of others. He could no longer move by himself and needed the assistance of at least one or two people to lead his daily life. He couldn't even go to the toilet, dress or bath himself or do other daily activities without assistance. At the beginning his family members were very supportive and sympathetic but when the financial condition of the family became severe, they grew tired of looking after him and a compassion fatigue became obvious among the family members. Their financial condition became so bad that they had to move to his sister's house in Sajahanpur. She had got married earlier to another barber who his father knew while working in Dhaka. The deteriorated condition of Bidhan's family made them decide to live with his sister's family in the hope of reducing family costs.

Discrimination by landlords because of disability

In Sahjahanpur six people live in a small room, including his mother, sister, brother in law, nephew, father and himself. His elder brother who is a barber sleeps in the shop he works at.

It was not easy to find a room for rent. When any landlord came to know about Bidhan's disability they refused to rent their room. Bidhan said that, "the landlord did not want to rent their room to our family because they thought we would not be able to pay the house rent since I am disabled. The landlords were also afraid about their rent because they saw I have no income – I did not even beg. On the other hand they thought that a disabled person would need much water and therefore the landowner owner would have less profit".

Compassion fatigue and narrowing of relations

Bidhan's dependency on others grew to such an extent that family members started to show irritation when providing him service and assistance. His elder brother got married in 2001 and has a child, both of whom moved to live in his in-law's house at their village in Bhola district. Having dependents, he is no longer able to help Bidhan as much as he did before his marriage. As a result Bidhan become unable to eat three times a day and started to live with the uncertainty of not knowing when he would have the next meal.

Bidhan's sister and brother-in-law only have a little income and they have to pay the house rent. Their only son (Bidhan's nephew) is at school and they want to him to complete his study. Bidhan's stay in their house is hampering his study since in the absence of the other family members, he is Bidhan's main caregiver. He helps Bidan pull his wheel chair, takes him to the toilet, baths him and changes his clothes. Though the toilet and bathroom is not so far from the room in which they stay, it is not an easy job for the nephew. He has to spend a significant portion of his time in caring for his uncle. Bidhan's brother and sister do not want

him stay with them anymore since they can't afford his cost and they often they tell him to commit suicide out of anger. They also feel that the investment they are making in their son going to school is going to become worthless as Bidhan damages his ability to study.

Bidhan's mother resorts to begging

Seeing no alternatives, in 2007 Bidhan's mother started begging to be able to provide food and treatment costs. She begs by asking for help from people by showing a picture of her disabled son and a leaflet. When Bidhan came to know that his mother had started begging for him he tried to commit suicide because this is the first time in their family history that someone has had to resort to such a low. Bidhan blames himself for this. According to Bidhan, "As a son I should take care of my aged mother but my mother herself is begging for me! Nothing can be more shameful than this for a son. It is better I should commit suicide and I attempted many times but even death for a poor person like me is not easy."

People in the locality know Bidhan well. When he goes out people willingly offer him food and some of them also give money (often 10/20 taka) to buy food for him. The occasions when he is able to bring food home are the only times his family behave well towards him. Otherwise no one except his mother even wants to know whether he has eaten that day or not. Bidhan's mother asks for help from people in the streets and goes door to door showing a leaflet with a photograph of Bidhan. She manages to get a little money each day but it is meagre compared to the cost needed for his treatment and food. Usually very few people trust a person when they see such a leaflet.

Access to safety net but too small an amount

From 2009 Bidhan has received disability allowance which was introduced by the Ministry of Social Welfare and is managed by National Disability Council. He came to know about the allowance from other disabled people in the area. He went to the office situated in Mirpur and finally his name was enlisted. However this only entitles him to 300 taka per month which is such a small amount that one cannot survive on it even for one week. Bidhan said that in order to collect this amount one has to invest a lot of time and energy. Sometimes he has to go to the office on more than two or three days. There is a long queue and it needs the whole day. Sometimes Bidhan thinks it is better not to take the money but when he thinks about buying medicine and food he changes his decision because when one has nothing then 300 taka seems a lot of money.

Social Support

In 2011 one of Bidhan's neighbours who was a good rich man helped him to give an interview on a TV program to raise money as part of the charity program. His neighbour

communicated with the channel authority himself and they agreed to take Bidhan's interview in one of their programs. The interview was televised on R-TV (one of the popular satellite TV channels of Bangladesh). It was a live program and instantly many people from different parts of the world rang up and made detailed enquiries about his disease. Many of them even promised for help and took his elder brother's bank account number. However they neither helped nor wanted to know about his condition later on. To Bidhan they promised to help only to show their sympathy when the program was airing.

Attempts to Suicide

Bidhan has become so tired of his poverty and disability that he has tried to commit suicide five times till date. Family members also tell him to die out of frustration. Two years back in 2009 he tried to commit suicide for the first time. On that day when there was no one in the room he intentionally fell down on boiled water (which was boiled by his sister to use as drinking water) from his wheel chair but he only sustained burns to his body. His neighbour rescued him later. Three months later he again tried to commit suicide. He went to a shop to buy poison but somehow the sales man realised that he was buying it for himself and refused to sell it to him. One day while going through a road he fell in front of a running bus but again he didn't die. He just severely injured his leg. Later one of his neighbours saw him injured and took him to the nearest medical shop and bore the cost of plasters and bandages.

Disability and Humiliation

Bidhan said that because of him the whole family is suffering. His brother-in-law often wants to divorce his sister since Bidhan has been staying with them. Many a time when someone is not there Bidhan remains hungry until someone gives him food. He also has to wait to go to the toilet until one of his family members attends him. Sometimes this means he has to spoil his cloths sitting on the wheel chair. If he asks for help from his immediate neighbour they used to say that they are not his paid employee. When people are disabled especially if they can't earn people do not give them even minimum respect. Bidhan shared his experience related to social stigma. Many times when people see him while going out for work in the early morning they rebuke him. To them he is a bad omen. Bidhan's brother and sister now can't tolerate him. Bidhan said, "I am disabled that doesn't mean I have no self esteem." When Bidhan is taken for a bath by his family members other than his mother, they make him be completely nude and Bidhan feels very ashamed but there is nothing he can do. In slum areas bathing places are shared and in some cases open.

Box 2: Discussion of Social Stigma Related to Disability 'Bad Omen'³

Many people in Bangladesh hold social taboos about people with disabilities (PWDs) based on stigma and ignorance. Little is known about disabilities in the public domain and comprehensive studies on the link between poverty and disability are lacking. This lack of information on the poverty of PWDs is indicator of their marginalized and invisible status in society. PWDs are not recognized in society as full members to be seen on equal terms with others.

Evicted by his brother-in-law

Last year Bidhan's brother threw him out of the house. Bidhan was outside for two days. He went to Narayanganj and stayed there the whole night in a bus station but fortunately the people who work there bought him food. The next day he was hungry for the whole day and become so weak that people at the bus stand forced him to tell them his address. They managed to arrange transport and sent him back to his home. According to Bidhan, "There are still some people who will take pity on you and offer help when you are in a wheelchair."

Brother tries to kill him

Bidhan's family were so tired of his disability and dependency that his brother once tried to kill him out of anger. In 2011 Bidhan's elder brother took him to the nearest canal when no one was around. He threw him in with the wheel chair to let him die, assuming the water would drown him. However, as the water was shallow he did not drown, and later after his brother had left, some people rescued him from the filthy water when they heard him cry out for help.

CONCLUSION

Bidhan's life trajectory is dominated by the role that his disability has played, and is an example of the dynamics of disability for extreme poor households, struggling to survive. Bidhan was born into a Hindu working extreme poor household that was severely affected by river erosion which destroyed their homestead land, and a subsequent cyclone which they destroyed then efforts to rebuild their lives living on the land of a local elite who took pity on them. Moving to Dhaka their situation was difficult though improved as Bidhan and his elder brother were able to work, enabling the household to have a comparatively decent diet. The situation dramatically deteriorated from the late 90s when Bidhan came to suffer from acute GBS. Paralyzing the bottom half of his body, he became completely dependent on his

³ Source: *DISABILITY IN BANGLADESH PREVALENCE, KNOWLEDGE, ATTITUDES AND PRACTICES, (2005)*, Accessed from: <http://unnayan.org/reports/Disability%20Prevalence%20and%20KAP%20Study.pdf>

household to survive. The household therefore not only lost an income but had to focus more resources (medicine, time) on Bidhan for his survival. In a household as vulnerable as his, this has become an extreme pressure, with the household struggling to survive. His mother has been forced to beg and his nephew's education has been threatened through needing to spend high amounts of time caring for him. They have also been discriminated against socially, finding it difficult to find accommodation, and in neighbours showing no interest or care for him. At the same time some people do show pity, though sometimes, as in the case of the tv programme, this is more good meaning than action. The psychological impact that condition has had is enormous. Bidhan feels isolated, rejected, humiliated and without dignity. He has tried to commit suicide several occasions and the strain on his household was so extreme his elder brother tried to kill him. The psychological dynamic to his vulnerability, and to forms of poverty more generally, is clear from Bidhan's story.

LIFE HISTORY MAP

Dates	Well-being movement	Reasons
1975-1984	2	Born into a working extreme poor household and attends school
1985-1987	Moves to low 2	Drops out of school and works as an apprentice in a barbers and is mistreated
1988	Move to 1	Cyclone destroys home and land
1988-1991	Stays at low 2	Migrate to Dhaka and live in difficult situation in slum
1992-1996	Moves to 3	Earns full wage as a barber, household situation improves
1997-2002	Moves to low 2	Develops GBS, works less, family dependence increases, and expensive medical costs
2004-2006	Low 2	Unable to work, completely dependent.
2007-2012	Moves to 1	Mother begs, Bidhan tries to commit suicide

Life history map of Bidhan Chandra Saha (37)

