

UMARI – CASESTUDY: SMILING THOROUGH LIFE CHALLENGES

Name: Kalpana & Vaishali

Location: Village Umari. Taluka Kalamb district Yavatmal in the State of Maharashtra

Form of Disability: Severe Physical Disability

Current Status/Occupation: Unemployed, dependent

Kalpna and Vaishali are a case in point of the plight faced by thousands of girls with disabilities in remote rural areas of our country. They symbolize the human spirit that refuses to bow down to umpteen life challenges. Despite severe physical disability, with difficult socio –economic background and almost no access to any facilities or services, they still are still optimistic about their future.

Born to Mr. Vasant Bari and Sindhutai whose family stays at Umari, Taluka Kalamb district Yavatmal in the State of Maharashtra, both of them seem to have some genetic problem which has never been diagnosed and properly treated till recently; when District Project Manager of Yavatmal district team of MSRLM visited the family October 2012 along with their Inclusion consultant.

Vasantrao – the head of the family and father of these disabled young girls is 45 years, illiterate Hindu male. His family came to this place before independence from a place named Jodmoha. Vasantrao's father also had a disability in one leg and his mother Kasabai has disability in both of her legs. Vasantrao has 3 brothers and one sister. All of them are non –disabled. They all are married and stay nearby.

In 1988 Vasantrao got married to Sindhutai. She is 45 yrs and has studied up to 4th std. They have 4 children - two boys and two girls. **Out of these 4 off springs, 3 are disabled.** Earlier Vasantrao used to look after the family by working on the farm of Mr. Rajendra Gandhi on Rs. 300/- per month. When the elder daughter Kalpana became about 9 to 10 years old, her hands and legs lost the strength. Though they treated her for that at nearby government and private health services, things did not improve and Kalpana had to leave school to stay at home due to her health issues. In another 2 to 3 years when the second daughter Vaishali became 9 to 10 years old, she also became disabled as a result of no strength in her lower and upper body. She also had to leave schooling when she was in 4th standard. She was also shown to local medical professionals without any fruitful results. In addition she was taken to *tantriks* from the area who literally looted money from already poor parents. This was followed by the similar health issues faced by son - Bhushan when he was about 9 to 10 years old. Due to inability in walking; he also had to give up schooling.

Vasantrao and Sindhutai are facing difficulties raising 3 severely disabled children in the same family. The situation gets more challenging as the financial condition is very modest. However, both of them have tried all possible treatments available in the area including *tantrik-mantriks* but for proper guidance regarding their rehabilitation.

Currently Vasantrao stays at home to look after the needs of their 3 disabled children. He sells biscuits and other snacks in the nearby Zillah Parishad school. Their son Bhushan also sells the snacks with the help of his tricycle, yielding about Rs. 1000/- per month. Sindhutai earns about Rs. 2000/- per month working as a labourer.

Kalpna is unable to perform activities of daily living such as toilet, bath, dressing up etc without help. She and Bhushan can manage feeding themselves once they are served. However in the case of Vaishali - she is unable to even eat her meals by herself.

Both daughters – Kalpna 22 years, Vaishali -19 years and son Bhushan have similar type of disability. All of them have disability certificates obtained by the father after lot of running around. But they are unable to derive any major benefits thru government or NGOs. Bhushan's Tricycle is in working condition whereas the girls' tricycles are not in good shape at all. As their only means of being mobile is not in usable condition, the social life of these girls is practically zero. They lead a much excluded life as a result of the lack of mobility. Yet they try to think of various options of livelihoods and hope

to get some assistance to live with dignity. The current home is kaccha type with *tina* roof. Last year when Vasantrao tried to request for financial loan through local Bank so that he could put up a small



Vasantrao with his wife Sindhutai and daughters Kalpna and Vaishali



Kalpna Bari and Vaishali Bari

eatery, he was refused on the pretext that the village has many defaulters and hence they cannot consider his case. Vasantrao and his family have no insurance. The government medical facility is about 10km away. Transportation is neither available, nor affordable.

Kalpana & Vaishali hope to own a small shop where they would like to keep supplies of daily needs one day. They count on their father and brother for procurement of these supplies. If some financial assistance is made available through SHGs or other schemes this dream can become a reality, they say.

The possibilities can be endless so that not only the disabled girls but the entire family may live with dignity and come out of current state of extreme poverty. With convergent action through various government departments, some of the assistance that could be planned as interventions are as follows -

- Working towards Indira Awas Yojna for housing since the family is already in the 2002 list of poverty,
- Insurance facility for girls and the family
- Provision of minimum work for parents through MGNREGA –,
- Medical help and counseling services along with referral and rehabilitation services as required.
- Provisions of assistive devices that can help the girls have life with mobility and socialization.
- Provision for continuation of their education is very important.

The NRLM team at the district level is trying towards achieving these. The DPM has already arranged for a proper medical referral at Mumbai and is also trying to help them to get loan through MSHFDC to set up a shop of their dreams.

- Equally important is creating awareness regarding various disability issues in the given community
- Various organizations within the community also need to be sensitized - especially financial institutions like banking facilities that can provide appropriate assistance / help the family.
- Exploring possibilities of Loans to the girls as individuals and / or through SHGs
- Village level organizations plan for specific livelihood options for such needy people

With overall key challenges such as -

- Accessibility and availability of basic health and rehabilitation services through various schemes and programs of MSJE
- Lack of appropriate assistive devices through appropriate schemes of MSJE
- Awareness regarding basic human rights through various Govt. and non Govt. programs
- Provision of right to livelihood under NRLM
- Need for appropriate medical, counseling and referral services under NRHM

It is high time that we better learn lessons such as -

- Counseling and referral services need to be made available for prevention of disabilities
- Appropriate medical and rehabilitation services to be made available in the unreached area (at least at the block level) for PwDs to live a life with dignity. It was clearly evident that the deterioration of all the 3 members happened due to basic lack of facilities within their reach.
- Financial institutions, health and all other govt. service providers are neither available nor sensitive towards the needs of this marginalized group. Thus awareness building and sensitization on various issues related to PwDs needs to be undertaken.
- Proactive steps need to be undertaken by all the stakeholder departments to recognize the basic rights of PwDs and create mechanism for addressing any violation of human rights so that they are able to lead a life with dignity in the community.

Last but not the least, it is humbling as well as encouraging to see this family with 3 disabled adolescents smiling through their life challenges and keeping their hopes alive! It definitely becomes the responsibility of both government as well as the community to kindle this hope and make it a reality.

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Notes

- *The case study was sent in Marathi by the DPM Yavatmal, MSRLM (District Project Manager) Mr. Yuvraj Mehtre and translated by CGM - Anagha Ghosh as she was not in position to travel due to health issues. However, the family involved in this case study was paid personal visit twice by the Inclusion Consultant to MSRLM - Mr. Samir Ghosh*
- *The consent form could not be filled up as it was not available with DPM at the time of the interview and second visit is not possible so soon. However, the family was forthcoming and was willing to share the information spontaneously and also gave consent to be photographed. They have been informed that this case study may be published.*