Case Study

Name: Anuradha Pareek Age: 36 Gender: Female Education: Master in Social Work (MSW) Marital Status: Divorced Highest education: MA, MSW Current self-employment/ employment status: NGO Employee Type of impairment: Locomotor (Orthopaedic) Any other members with disabilities in family: No

Anuradha, a 36-year-old woman with disability who belongs to Denwa in Dungargarh block of Bikaner, Rajasthan, narrates her story which is full of continued struggles, disappointments, learnings and achievements. When she was 15 months old, she fell in the 'chulha' (stove/fireplace) and got burnt while playing in her house. She couldn't get proper health care in the local hospital as the doctors weren't skilled to deal with burnt cases, which resulted in deformities in her body especially loss of hand fingers. Interview unique number: 01 Interview date: 29/11/2019 District: Bikaner State: Rajasthan

Anuradha stated, "Hospital was 15 kms away where she was admitted. There was no burnt case specialist there. They took me in a camel cart as there was no other conveyance. Due to poor treatment got deformity and lost my hand fingers completely. Doctors would visit me but they didn't take my burn & swelling seriously"

Witnessing the seriousness of Anuradha's condition, her uncle

took her to the Bikaner district hospital. She was admitted there for six months, and her mother and grandmother stayed with her.

"I received better attention at the district hospital, however, by the time I was admitted, both my hands were already impaired. My skin marks did not get cured till date because of doctors' negligence in village hospital and I am labelled 'disabled' throughout my life."

She was seven years old when she first started going to the school. She describes that she didn't experience any discrimination in her education and was supported by everyone- her family, school friends and teachers. However, she did mention that there were two other girls with disabilities in her school who dropped out early and got married.

Anuradha describes her school experience as,

"Up to class 11, I used to be afraid mostly and I would think that no one finds me beautiful. I was not very good at studies but good at writing. I feel awkward when I travel because people use to stare at me and asked taunting questions 'were you born like this'. I didn't face any obstacle while accessing education and got good support. I was never discriminated because of my disability in schools and college but I felt inferior to other female friends who looked 'normal' and I was made to feel 'abnormal'. Till 11th standard this inferiority complex continued, however, in 12th standard I got motivated by a friend and started coming out of my 'shell'."

Anuradha has been in an abusive relationship with her husband and because of his extreme violent behaviour and drinking habits. He used to physically and emotionally abuse her and also killed their son. Anuradha could not bear the pain of her second child loss and also was mentally traumatised for years.

"Being a divorcee and not wanting to have a second marriage, I enjoy being single as it is epitome of independence and freedom. I counsel other WwDs when they crib of not being to find a good life partner and want to get married to anyone of family's choice" Anuradha explained, "I used to be very religious and believed that I should be submissive and follow my husband everywhere. I had always been a devoted wife. He used to hit me and I never said anything to him, rather quietly bear everything. For seven years I went through all of this. One day when my husband came home drunk and became angry as I couldn't prepare food on time as I was busy handling my second boy child. In anger, he killed him by throwing him twice on the wall, then on the floor and finally in the bed. My child was dead but I continued to nurse him assuming he is injured and he will get well. But he was declared dead when I took him alone to nearest hospital. I did not complaint about my husband being a murderer but defend him again."

She decided to reach her home town and get divorce. It was challenging but with her mother and mother-inlaw's support, she managed to get divorce from her husband. Overcoming her struggles, she learned her rights of being inclusive and empowered hard way, but with positive attitude and as a responsible member of the society, she now counsels and supports other women with disabilities (WwDs) who face domestic violence.

"I think violence is also about 'exploitation. When I have gone through domestic violence, I needed more family support but there was no social security or support from government for women with disabilities who suffered violence. Above all, there are no shelter homes for us".

Anuradha emphasized another significant aspect where WwDs are tormented, especially when they are pregnant. She describes the scenario as follows:

"During childbirth, WwDs are taunted when they scream during labour pains. The nurses are very rude to these women. They usually said, 'you didn't think about it when you had fun with your husband, then now why are you shouting.' Even during my first pregnancy, my mother told me not to shout or cry during delivery because she said that it is a sign of weakness. I bit inner lips with my teeth because I tried not to shout. It was very painful for me. My lips were swollen for days. Later, I realised how patriarchy dominates in our community. We should be the one to give life to a male child but could not express our pain!! These societal attitudes are strongly oppressive in nature towards WwDs and people need to be made aware about the rights of WwDs as a human first and then disabled".

Anuradha is a strong, empowered woman and is respected for her work and contribution in the village. She is a proud member of 'Panchayat Samiti' and is admired for her power and position to carry out advocacy and help finding solutions to the various issues of persons with disabilities (PwDs).

Anuradha proudly states, "I am known in my village for my work and contribution. My father is known for my work and people say 'look Anuradha's father is going.' I feel proud and confident that now I have an identity."

Being financially empowered helps in reinforcing the confidence, thereby, it helped Anuradha in making decisions for financially secure future. She affirms, "I have my own property and have now invested in gold to secure mine and my children's future."

She represents WwDs from her area at the 'Social Welfare Department' and mentioned that even the Department discriminates against WwDs. She stressed that if someone from her village is to be nominated for a post in the DPO, she always faces taunting and dominance from the male DPO members.

"When there is visibility of WwDs required during events/seminars; 'I am invited,' however, in an urgent decisiontaking meeting where my representation is necessary, 'I am not called." Anuradha, is proud of being trained on Sustainable Development Goals (SDG) and Rights of Persons with Disabilities (RPWD) Act in training workshops organised by Sightsavers and Samarthyam under EU project. She has developed clarity about rights of WwDs and she imparts training to others so that 'no one is left behind'.

Anuradha highlights the significance of above as:

"Accessible environment is very important under the SDGs. I am actively advocating for it and it has been implemented in few of our neighbourhood streets. I have also got 'sewer lines' maintained, which were overlooked earlier and dirty water was entering our houses. Implementation of accessible environment helps not only PwDs but everyone. I want good roads, light and cleanliness in my village. I am also fighting for accessible public toilets for WwDs and advocating for a school toilet facing the market within the school premises."

With her enthusiasm and enlightment on rights of women with disabilities, she has made her own identity in her DPO and attended SDG-UNCRPD-RPWD gender assessment training, score card training, leadership training and accessibility audit training. In health sector, she has been advocating to have more hospitals and more female doctors. She came across a female sarpanch (village head) who was on hunger strike to have more female doctors in village and block level, and she supported the sarpanch.

Anuradha shared the following in one of her DPO meeting: *"I want to implement SDGs strongly as now I know how to advocate for SDGs in rural settings. I can connect the SDGs with the e-sakhi technical training and provide expertise to other co-trainers about connection of SDGs with lives of people at local level."*

Anuradha proudly narrated her exchange visit to Brussels during the EU project. "In exchange visit to Brussels, I learnt that in India 'we count how many people are there in a DPO', however, after the visit I understood that we need to learn 'how many DPOs are linked with our DPO. Infrastructure accessibility in Brussels motivated me to advocate about it in my district. I loved digital accessibility and app usage to identify public transport system. Example of train coach and train seat identification in the train by 'beeper' audio is marvellous and I cannot ever forget it. There was a blind person with guide dog and he was highlighting the need of relieving areas for dogs in airports as guide dog relieving areas are not available in public spaces in Europe also. I was surprised that in my country we do not talk about accessible village/block, as accessibility is still considered an urban need."

Anuradha suggested some of the following interventions:

- School should provide scribes for children with blindness and children with upper limb disabilities
- Curriculum in each class should have awareness on disability. This is found in many states, however in Rajasthan this is still not practised
- Assistive devices should be available on time as per specific disability requirements and there should be facility for their maintenance
- WwDs should support each other. There needs to be strong sense of 'sisterhood' and we need to nurture it
- Provision of female attendant with WwDs during travelling for work in inter city/district travel
- It should be mandatory for DPOs, Sightsavers, and partner organizations, to provide personal support system by means of assistant and advance amount during travel. No late evening or early morning travel should be encouraged

"Anuradha's Moment of Honour"

I never thought of getting into politics, but a small discussion led me to do so. One day, while I was in the field discussing with the disabled peoples' organization about their rights and entitlements, a member asked me, 'Why don't you contest for the post of panchayat raj representative in the 2015 election.' I replied, 'I will be happy to contest for the higher position.' The discussion reached my family as well.

One day, without informing me, my brother went to the office of a political party and nominated my name contesting for 'Member of Panchayat Samiti.' I was surprised to see that my name was shortlisted and that too not just because of my supporters but my engagement with the community for the last three years as well as my knowledge on social issues. My knowledge on social issues, government schemes, policies, Acts, among others, were enhanced through engagement with Urmul Trust. My experience of working with disability, women empowerment and old age people, benefited a lot. When my name was shortlisted my reputation in the community started to growing and people started identifying me.

When I became the member of 'Panchayat Samiti' my self-confidence increased. My existence in the community became stronger. People started to call my parents and family by my name. My parents also praised me 'you have attained high respect and level' and keep doing good work so that others benefit from it'.