

# SHANTA MEMORIAL REHABILITATION CENTRE ASHOK HANS FOURTH DISTINGUISHED MEMORIAL LECTURE



Deepa Sonpal is a highly recognized international human rights disability activist. She is an author, researcher and development thinker, on issues of disability especially women's rights. As a woman with a disability herself she brings personal experiences to her work.

Deepa has combined her extraordinary skills to help other women with disabilities to achieve heights of exemplary strength.

# Knowing is not enough, we must apply. Willing is not enough, we must do!

Respected elders, dignitaries, fellow Sisters and Brothers! It is a matter of great honour for me to deliver the Sixth Shri Ashok Hans Memorial lecture. On this auspicious, occasion while we commemorate the vision envisaged by Ashokji that is being accomplished through theactivities undertaken by the Shanta Memorial Rehabilitation Centre (SMRC), I would like to thank Ashaji and Reenaji for bestowing me with this opportunity deliver this memorial lecture and to meet you all.

We all already know that in a patriarchal society like India, women with disabilities are doubly discriminated on grounds of gender and disability. To this is added the burden of intersectionality of caste, class, race, religious ethnicity, migrant status, sexual orientation and geographic locale. Globally persons with disabilities comprise 15 percent of the population, of which 80 percent live in developing countries and 19.2 percent of the women population are affected by a disability.

In India the estimates are much lower. A majority of persons with disabilities are invisible as we do not even have a count of the exact numbers. There are various reasons for the variance in the estimate of prevalence rates that range from social stigma to various other technical problems related to its enumeration, like definition of disability,

orientation of enumerators, the methodology used for data collection and the politics of exclusion. Persons with disabilities are not yet recognised as citizens of the country as they do not even poses a voter identity card and are not considered a vote bank by political parties. The census 2011, like the previous one conducted in 2001 claim that around only 2 per cent of the population is disabled. Out of the total disabled population 45.5 per cent cannot read and write and among women this is even higher. The figures for higher education are very low with only about 9 per cent men and about 7 per cent women manage to complete their graduation. Literacy rate and skill sets are directly related to employment. In a competitive world only the meritorious will get the opportunity to be gainfully employed. Only if the basic needs of individuals with disabilities are addressed will they be in a position to collectively take action for themselves as well as for others.

Disability like gender is a social construct and culturally stigmatised emanating from the notions of a perfect being'. It is the barriers in the environment - social, cultural, economic, institutional, legal to information, technological and physical that gives rise to a disabling situation. Women with disabilities are considered a-sexual but, ironically are four times more likely to be victims of physical, sexual and emotional violence than their peer non-disabled women. It is the near and dear ones who most often cause harm or discriminate against us, little knowing that they themselves maybe caught up in such a situation, as disability is something that may affect anyone anytime in their life span.

Living in a world that has the best possible technological evolution, that has the capability to provide options for all kind of users, why is it that large number of people continue to be marginalised, victimised, alienated, discriminated, oppressed and bereft of opportunities that is their right as a human being? There are several international treaties that highlight human rights, specifically focuses on non-discrimination, equality and so on.

In this instance I would like to quote the path breaking UN Convention on the Rights of Persons with Disabilities (UNCRPD) that clearly demonstrates what Helen Keller had said centuries ago that, "Alone we can do so little, together we can do so much". Internationally, the CRPD is proof of this fact. Now even the Sustainable Development Goals (SDGs) 2030 Agenda have acknowledged the inclusion of disability in select goals. Out of the 169 targets across 17 goals, five explicitly mention disability and there are several others wherein disability gets covered on the basis of universality of its applicability under the policy slogan, 'Leave no one behind,' The five specific goals of the SDGs are:

- (i) Guaranteeing equal and accessible education by building inclusive learning environments and providing the needed assistance for persons with disabilities,
- (ii) Promoting inclusive economic growth, full and productive employment allowing persons with disabilities to fully access the job market,
- (iii) Emphasizing the social, economic and political inclusion of persons with disabilities,
- (iv) Creating accessible cities and water resources, affordable, accessible and sustainable transport systems, providing universal access to safe, inclusive, accessible and green public spaces,
- (v) Underlining the importance of data collection and monitoring of the SDGs, emphasis on gender and disability disaggregated data collection.

The CRPDis is the the overarching vision and guideline globally accepted for inclusion and mainstreaming disability.

The CRPD specifically highlights in its Article 6 that women and girls with disabilities face all types of discrimination and that their human rights should be protected. Recently we worked with eight disabled person's organisations (DPOs) in India to enable them to do a situational analysis and capacity assessment. The DPOs in India are at a nascent stage and are faced with numerous challenges of organising and mobilising persons with disabilities. It was found that persons with disabilities experience profound exclusion, have limited access to information, mobility is affected due to barriers in the environment, are living in scattered locations, are mostly struggling to access the benefits of government schemes and a large part of the battle is in obtaining a disability certificate, the diversity within disability is a challenge as a result of which the self image of persons with disabilities and particularly women with disabilities is very low. During in-depth discussions with DPOs it was acknowledged that within their structure there is very little participation of women with disabilities in the decision making processes. Specific efforts need to be made to invoke the participation of women and that they need to be empowered and their voices be heard. The lived experiences of women with different kinds of disabilities from differing socio-economic backgrounds need to be collected to gain deeper insight into the needs and aspirations. As a person with a disability I completely believe in and advocate 'nothing about us without all of us. 'This is not to say that we do want the support of our family, peers, friends, relatives, colleagues in our journey of life to gain our rights on an equal basis with others, but we must assert our rights as well.

Marginalised groups are only able to assert their rights if they undergo a process of concentisation - as propounded by Paulo Freire. Persons with disabilities need to dialogue and critically analyse their social reality and collectively take action to transform their environment by again critically reflection and taking action - this continues process of reflection-actionreflection followed by action is known as praxis. The questions then we need to ask collectively as well as individually are: Why are we labelled as disabled? What are the barriers in the environment that are limiting our participation in leading a dignified life? How could the barriers be eliminated or minimised? How to break the various barriers specifically related to the theory of karma that mainly stigmatise persons with disabilities? What needs to be done to change our situation? Who will take the lead in changing this situation? How to increase the confidence levels of persons with disabilities? Who will support us in our struggle? How can we make our voice heard? What is it that will enable us to lead a dignified life? These are some of the questions that need to be answered and action needs to be taken to change the situation so that all groups of persons with disabilities benefit from it.

The challenge then is how to be able to transgress the boundaries of bodily integrity. How can we dive deep within ourselves to overcome our own notions of the 'perfect being' defined by societal and cultural norms and let the beauty of the soul shine out. It needs to be realised now more than ever, when there is so much unrest prevailing on this earthly existence, by all human beings, that all our souls are the similar and that we are parts of the same source. An old saying goes that if you dig a well for the other you may fall into it. So if we are all parts of the same source how can we think,

feel and express dislike and haltered for the other or in this sense our own selves? Christ said that, "Do to others as you would have them do to you."

On this auspicious occasion let us together celebrate diversity and pledge to develop a new world order, to instil values of sincerity, commitment, mutual respect, integrity, empathy, tolerance, humility, compassion and contentment by leading a lifestyle of conscious living where no one is discriminated, enjoy equal opportunities and live a life of dignity. Each of us can do our little bit wherever we are placed in whatever capacity to be alert and make life meaningful for the other. Let our intuitive capacities be our guide as rightly said by Helen Keller, "The best and the beautiful things in this world cannot be seen or touched. They must be felt with the heart."

Acceptance and perseverance is the key to achieving a place of respect and equality for all in order for humanity to be emancipated and liberated. Giving ones best in these given circumstance where the intention or the 'niyat' matters. As rightly said by Vivekananda that, "All power is within you. You can do anything and everything. Believe in that. Do not believe that you are weak.....Stand up and express the divinity within you. Arise! Awake! and stop not until the goal is reached!



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