

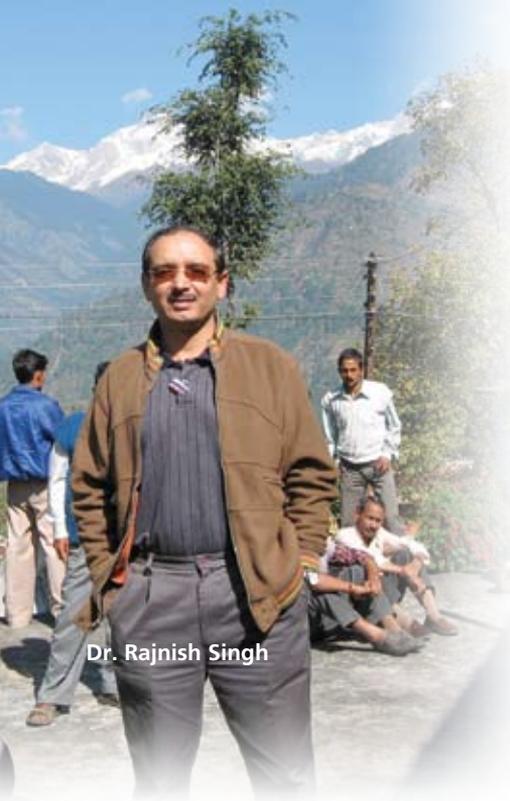
SAMVEDNA

Dr. Rajnish Kumar Singh

Samvedna is providing a valuable service to people in the remote hill areas of Garhwal by arranging medical camps and further specialized treatment and follow-up in Dehradun. The primary focus is on the mentally and physically challenged children or young adults. These are people who might not have ever seen a qualified doctor or do not have the means or motivation to undergo treatment on their own.

My first Samvedna camp in Sumari, Rudraprayag district was an eye-opener. It was a sobering experience which made me realize that a lot of things that we take for granted in our day to day lives are beyond the means for many. I saw patients with club foot over twenty years old who had never seen a doctor! Little children with preventable burn contractures. I was frustrated, angry and sad that so many children had unnecessarily lived with correctable deformities for years and years. But I was also inspired by the commitment and enthusiasm of many of the Differently Abled volunteers like Sujan Singh, Parvati, Minakshi and Shiv Dei.

The difficult life of the differently Abled is further compounded by superstitious beliefs, illiteracy, inaccessible and inhospitable terrain, lack of awareness and poverty. In the first camp itself I was surprised with the high number of mentally challenged children that came. It appears that their situation was mostly a consequence of home deliveries conducted by untrained dais (traditional birth attendants) in unhygienic conditions,



Dr. Rajnish Singh

birth injuries or head/burn injuries in early childhood.

Subsequent camps made us realise that there was an urgent call to address the needs of the many mentally challenged. Hence, a Special Needs Centre was started in Tilwara, Rudraprayag. For this we have to thank Mrs. Jo Chopra and her dedicated team of workers at Karuna Vihar, Dehradun who helped train four volunteers. There is much that remains to be done in this area.

Samvedna program has enabled us to make a big difference in the lives of many physically challenged children. Until now we have held six camps, screened over 3000 patients and performed surgeries on over 40. These are all under regular follow-up and our care. Personally it has been a

very rewarding experience. The look of gratitude and appreciation from the parents and smiles on the face of our young patients are memories that will stay with me forever.

For such a mission there are numerous challenges that we face. Patients have to be motivated to initially come to these camps and then to Dehradun for specialized treatment and follow-ups. Many families do not understand the importance of continuing the exercises at home and prosthesis adorn many a wall - unused!

Mobilizing people from very remote areas could involve a three to four hours walk to the nearest motor able road, a task which has only been possible due to our team of dedicated volunteers.

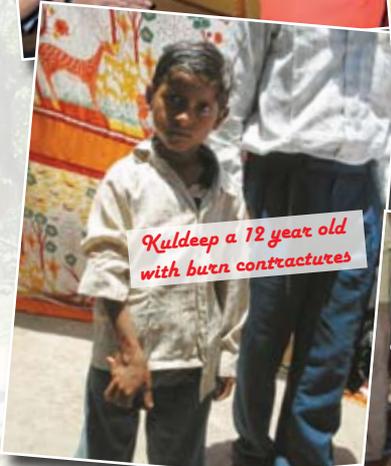
Our future plans include organizing camps, especially meant to educate the rural community regarding medical problems, increase volunteer mobility and access, raise awareness about disability and change negative



Kuldeep after surgery



*Mukesh
a 22 year
old never
visited a
doctor his
entire life...*



*Kuldeep a 12 year old
with burn contractures*



Before Surgery



*12 year old Vijeshwari
with burn contracture*



*Recuperating after
surgery*



Vijeshwari after surgery

attitudes. With valuable lessons learnt over the past two years we hope to extend the reach of Samvedna to other districts of Garhwal.

I am grateful for the privilege that God has given me to serve through Samvedna and would like to invite other colleagues from the medical fraternity to become part of this initiative. It is my dream that five years from now no child in Garhwal will be compelled to live life with a correctable disability.

Dr. Rajnish Kumar Singh, Orthopedic & Trauma Surgeon, MS (Ortho), FRCS (Ed.) FRCS (Glasg.) UK, ALTS (UK) is the Medical Advisor / Consultant to the Samvedna program.

He volunteers his time and professional skills to the program. His commitment and enthusiasm are a very valuable asset of Samvedna.



Our dedicated team of Doctors

AGNES HUTTENLOCHER

(Agnes Huttenlocher, a Paediatric nurse from Germany who visited KHW-India and provided valuable services to its Special Needs Centre in Tilwara, Rudraprayag. She shares her experiences with us...)

I stayed for one month in the Special Needs Centre at Tilwara. This centre caters to the needs of the Differently – Abled' in the remote Himalayan district of Rudraprayag. I worked with a team of highly motivated volunteers under the project Samvedna. I was amazed how they could create things out of nothing and give the 'Differently-Abled' children hope and a chance to better their lives.



Agnes with Samvedna volunteers

My visit was during the cold winter month of December. I was told of the daunting conditions that the volunteers have to face but it was only with my experience and work in the region did I fully understand the challenges they faced on a daily basis. With no electricity and water, life in

the mountain region of rural India is hard.

During my stay I keenly observed the lives of the women in the mountains. The women work very hard and not only carry out household chores but also shoulder responsibility of feeding their families by working in the fields. Due to their impoverished conditions and poor awareness women and children suffer mainly from malnutrition. One of the pressing issues in the mountains are the under developed health systems. Most rural people have no access to an Outpatient Department, Doctor or trained midwife. People walk nearly 20 kms or more to get to the nearest hospital or trained medical person.

I have beautiful memories of the region and its people, but one memory in particular I will always cherish. My experience with a young boy named Sagar, a nine year old who came to the centre with his mother. His mother carried him on her back all the way from her village. I couldn't

help but appreciate her commitment and determined willingness. She placed him in a sitting position and placed his arm in such a manner that he could balance his own body. His limbs had no coordination and he could not do anything. As I spoke to the mother I was informed of a complicated pregnancy and an unsupervised delivery which was conducted by untrained women, a practice prevalent in the villages. I was told Sagar did not cry for the first five days. Her mother said that they believed that he suffered from cough and cold and this restricted his development.

There was no coordination between his visual perception and movements. I identified Loco- motor discoordination, delayed speech development and a complete retarded development because of a missing or delayed feedback of all groups of muscles. After an evaluation we did not find any stiffness or tightness in his joints which was a positive sign as it gave us some hope for him.

My aim was how to make him walk. How to increase the coordination between left and right hand. How to enable him to perform his daily activities like eating food, changing clothes, etc. and how to reduce his dependence on people around him. Sagar's mother was also guided on how to make her son exercise, take care of him, what food he required to eat etc. Along with the volunteers I developed an individual therapy-plan for Sagar for the next three weeks. This plan included physiotherapy, logopaedic exercises and also recognition of daily objects and making him aware of his environment. As days passed by Sagar was brought everyday to the centre and he would show consistent signs of improvement which would boost his self-confidence. After three persistent weeks, he attempted his first steps with a slight help. His face was radiant with pride.

Sagar is now a happier and more confident boy. He can walk several steps without any help. With his mother holding one hand he now walks daily to the center. His ability to recognize objects and people and also to articulate have improved. If Agnes were to see him today she would feel delighted to see the outcome of a process she had initiated eighteen months ago.

Inspite of the challenges like the difficult landscape, poor infrastructure, difficult accessibility, superstition, tradition and



Sagar

a general lack of health awareness KHW-India feels that it has started to make a difference through Samvedna. Sagar is just one of the many whose life have been touched and changed for the better.

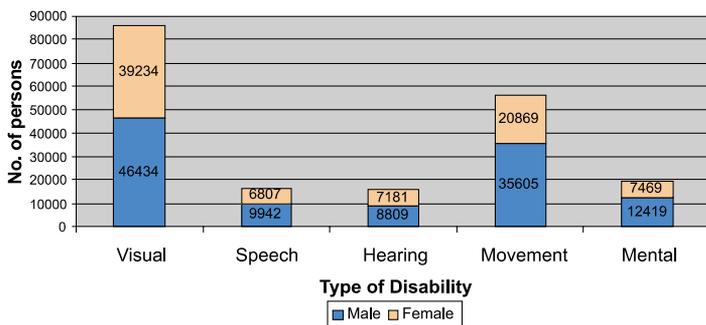
According to the WHO, 10 % (600 million) of the world's population has a disability. Of these 80% live in developing countries. However, definitions of disability differ from country to country and mild to moderate levels of disability just pass. But nonetheless they suffer social exclusion and therefore are

further disabled. A lot depends on how culturally disability is constructed, perceived and admitted. 75 % percent of the people with disabilities live in rural areas. About 49% of the Differently Aabled are illiterate and only 34% employed. These figures draw a bleak picture of the Differently Aabled.

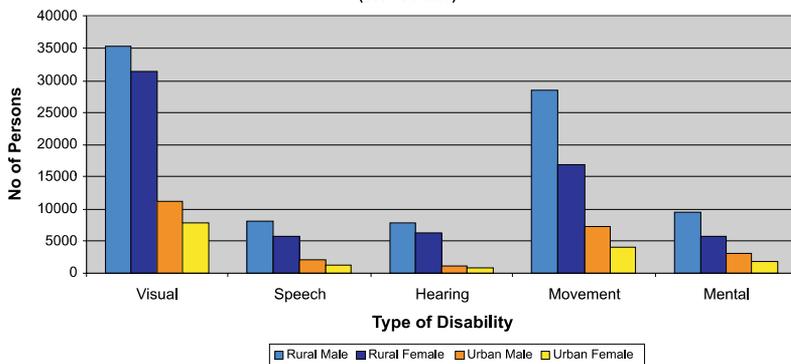
As per the 2001 census, 21.9 million people, constituting about 2.13 % of the country's population, suffer from disabilities. Some estimates say that almost 70-80% of Indians with disabilities live in rural areas regrettably most of the country's hospitals and rehabilitation centers are situated in urban areas. To transport

Disability in Uttarakhand

(2001 Census)



**Rural - Urban Distribution of Disability in Uttarakhand
(2001 Census)**



the rural Differently Aabled person to these centers for treatment, appraisal or training is difficult, time consuming and an expensive process, involving not only the cost of travel but also the loss of daily wage for the escort.

The rural Differently Aabled are at a disadvantage due to poor access to resources, employment opportunities and rehabilitation. They hence comprise the most neglected, marginalized and unlettered of their community. They are usually denied education and the right to enjoy normal social interactions and relationships.

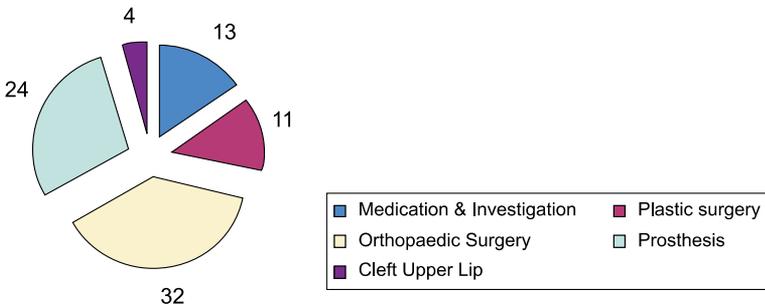
To be born into rural poverty in India is to begin life with a handicap. For it often means a helpless and stoic acceptance of a variety of socio-economic injustices. If in addition, a person belonging to this large segment of the rural poor is born with, or due to some unfortunate circumstances acquires, a disability, then s/he must face life with a double handicap. Every problem that confronts the able-bodied, afflicts the Differently Aabled person in a more intense and chronic form. What truly disables people are the various social and physical barriers and negative attitudes, which prevents equal participation in community life. Hence, disability is accentuated as a result of social exclusion and discrimination. Poverty must therefore increasingly be defined in terms of social disadvantage and social exclusion.

It has now also been established that segregation of the Differently Aabled into protected environments and special institutions is not

only dehumanizing but also prohibitively expensive, allowing only a very small percentage to avail of the facilities.

Samvedna encourages children to stay within their families and their communities to get the necessary therapy instead of moving them into institutions. It promotes Community Based Rehabilitation (CBR) by sensitizing, informing and empowering them to take care of the Special Needs themselves.

A Glimpse of KHW's intervention through Samvedna



Each Differently - Abled child is carefully examined and evaluated in order to best meet his / her specific need. Every child's physical and occupational therapy is decided along with the family, community health and rehabilitation workers. Our work includes physiotherapy which helps them improve position, movement, strength, balance and control of the body. We also involve them in enjoyable activities and finally provide them with social and economic rehabilitation.

Government intervention is inadequate because the care of the Differently Abled comes somewhat low on their agenda when compared with the more pressing problems of providing food, drinking water, health care, primary education and housing. The issue of disability does not generate enough interest within the government. It is still covered under the Ministry of Social Justice & Empowerment. We are yet to see a separate representative ministry which we strongly feel is necessary to compassionately and adequately address the needs of the Differently Abled in our country.