Answers to queries (May 2010)

(a) What is the right to health 2009 bill?

The <u>National Health</u> Bill, 2009, seeks to provide health, health equity and justice for **all** Indians. And makes a reference to UN Convention on Rights of persons with disabilities (UNCRPD): Article 25;

http://mohfw.nic.in/nrhm/Draft_Health_Bill/General/Draft_National_Bill.pdf

Organizations working in the disability sector have time and again looked at such legislations like even Right to free and compulsory education with a disability scan and if the legislations are inclusive of the issues and concerns of persons with disabilities

(b) Geetadidi, you had mentioned during our phone conversation that one of the children underwent a surgery, and the condition deteriorated. For our information, we would like to know more about what type of a surgery it was?

Narayan Sewa Sansthan of Udaipur is an NGO committed for all round development and rehabilitation of the disabled- particularly the polio afflicted and those born with disabilities. http://www.narayanseva.org/Default.aspx

The surgery that was done was for Hamstring release of Lower limbs as he had developed knee flexion contracture. Our visiting orthopedic surgeon had suggested against this but the parents went ahead with it. After the surgery, we approached the parents for follow up too and informed them about the Orthopedic camp and though parents promised but have yet not come to the centre.

Few parents of beneficiaries with Cerebral Palsy in their search for permanent cure/ one time treatment have gone there for surgical intervention as:

- the intervention is free of cost
- pressure from their social network for a treatment
- regular advertising by Narayan Sewa trust on religious channels that works on their psychology
- technically, the surgeries are good but the impact has not been encouraging as it lacks a holistic approach specially on children with disabilities as
- a. the follow up therapy did not take place as actively as it should have taken

b. in an effort to find a one time cure for children parents overlooked their own motivation and long term therapy inputs that were required for the child. (c) During your medical camps, KWS does not provide medicines, but we do when doctors prescribe medicines, apprise the docs about the financial position to ensure the continuity of the treatment so does KWS provide them? that they prescribe economical drugs. This is especially in case of children with Seizure Disorders, as some of the medicines are costly and have to be taken on daily basis for 3-5 years. Our visiting pediatrician is a private practitioner too and she often links up other donors for such cases. We also help in linking up with Government's District Hospital for the medicines that can be procured from there free of cost. We have a different approach and format for (d) Do you have awareness camps in your outreach program? activities to generate awareness. In our outreach program, we hold a large number awareness camps/events (this year more than 30) around Gurgaon and in Bangalore (our Chairperson Mrs. Savakoor is based in Bangalore) selectively to draw participation of Companies and their employees, and amongst interest groups, towards issues of disability mental disabilities in particular, and also invite their support for Khushboo's operations. We have in the past also occasionally participated in/or organized programs for the society in general, to voice our support for the rights of persons with disabilities. Do you use newsletters to generate Our quarterly e-newsletter, giving a bird's-eye awareness? One of our projects, view of our activities over the quarter, is RMKM, based in Rajasthan, prints circulated electronically to a wide spectrum of about 5000 newsletters, to reach individuals and interest groups connected with out to the community us in any manner. We have not considered it distributing them in fairs, door-tonecessary to print it and circulate or distribute door, etc. Does KWS adopt a similar it publicly to others, and doubt if it would be approach? cost effective in our nature and scheme of operations. Such action may be more suitable for the activities of Rajasthan Mahila Kalyan Mandal (RMKM) whose focus seems to be more on integrated community development approach, centered around economic uplift of women and others.

(e) We support three special needs schools in India for children with mental disabilities. Shristi and RMKM have been in contact with each other after initiation by Asha Austin. The general feedback is that both of these schools learnt a lot from each other. We were wondering if KWS would like to interact with these two schools too, and learn/share with each other?

Yes, we shall be happy to interact with Shrishti Special Academy, Bangalore and such other organizations, to develop into reality some of our dream plans for (a) Respite Center for Working Couples with children with mental disabilities, and (b) An effective Community Based Rehabilitation Program for those who are not able to avail our Center Based services.

(f) What is the normal internship period for the interns at KWS?

It is largely dependent upon the organizations that send interns and the time slotted for the same.

- (a) those students who are placed by their respective institutions as part of the academic requirements like Students doing Masters' in Neuro development Therapy, Special education or Social Work,
- (b) fresh candidates who after an initial period of hands-on experience under our guidance and observation can be eventually absorbed in employment with us.

This year we have had 1 student who came to us as part of the Community Program from US