

## **Lessons from India**

### **Advocacy for Empowerment: A Movement Away from Charity to Rights**

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The history of India's disability rights movement is very young compared to other movements. It was only in the early 90s that the seeds of a rights based movement were sown. Prior to that, disability was viewed from a charity and welfare perspective. The disability sector was controlled by Non-Governmental Organisations (NGOs) with either parents or professionals at the helm of affairs. All these NGOs were working in silos – without any connection to each other. Most of these organisations were working only for a particular disability – organisations for the visually impaired, for the hearing impaired, for persons with intellectual disabilities and so on. In the early 90s, a slow paradigm shift began.

#### **I: CROSS – DISABILITY MOVEMENT:**

**Disabled Rights Group (DRG):** In 1993, a bunch of disabled leaders met at the American Centre for a video conference with Joseph Shapiro to discuss his book 'No Pity' on the American disability rights movement which started in the 60s. "Why can't we have something like this in India?" I wondered. And thus, the Disabled Rights Group (DRG) was born - a cross-disability, non-political advocacy group. It is a loose network, more like an umbrella under which likeminded disability organisations come together for common objectives and goals. Despite the fact that DRG hasn't been registered till now, has no funding, no bank balance, not even a bank account and has no rigid membership, it has become a national level force to reckon with.

Over the years, DRG has successfully advocated for several rights based initiatives for empowerment of persons with disabilities: India's first disability law of 1995, getting a chapter on disability in the XIth Five Year Plan (which plans and allocates funds for development) and very recently, getting the Government to go in for a new disability law based on the letter and spirit of UNCRPD.

**National Disability Network (NDN):** The idea of forming a national level disability network came from the need to build a strong cross – disability rights movement in India. To create a movement, it was important to link disability groups around the country so that they could share ideas and participate in the decision- making process.

## Objectives:

- To promote local advocacy groups and **build leadership** in the disability sector.
- To facilitate local advocacy groups to join hands with state-level groups to eventually form a National Network that will act as a **pressure group** to influence meaningful policies at various levels – village, block, district, state and national – regarding persons with disabilities.
- To empower disabled people and organisations and to sensitise other concerned sectors through **systematic information dissemination** on disability related issues like legislations, relevant policies, research findings and current developments.
- To closely monitor and **jointly lobby** with the governments, corporates and other allied sectors to advocate the adoption and implementation of appropriate policies and legislations.
- To bring issues related to disability to the **forefront of national development** through a network that will have representation from all states, union territories and districts of the country.
- To build a **common cross-disability platform** for sharing of concerns by disabled people from all the corners of the country and to build a joint strategy for a cohesive disability movement in India.

## II: GETTING THE NUMBERS RIGHT:

At the beginning of the disability rights movement, the disability sector was faced with a unique problem – that of numbers. When DRG was lobbying for the disability law in 1995, we were always asked about the total population of persons with disabilities in India. What percentage of the country's population is comprised of persons with disabilities? Pertinent questions. But the truth was that until then no efforts were made to count the population of disabled people in the country in the Census. Although, a popular estimate among the disability sector leadership was 10% (based on some UN study), government surveys suggested less than 1%!!

Getting the numbers right is very important as all schemes and plans of the Government and allocation of funds and resources to be spent on issues is directly proportional to the size of the population it affects. Therefore, if disability is under reported, the funds allocated to be spent on disability are much lower than what is actually needed for getting all the aspirations of the disability sector like education, employment, access, etc. translated into reality.

India's population Census is held only once every ten years and the next Census was to be held in 2001. After a prolonged advocacy, a question on disability was finally included in the Census 2001 questionnaire at the last minute. Even with very little awareness and training, we still got a figure of 2.1%. India finally accepted that 21 million of its citizens were people with disabilities!!

The next Census of India will be in 2011. NCPEDP and DRG are already working towards getting the numbers right this time around. We are working closely with the Census Commission.

**Progress so far:**

1: Question on disability revised to include more categories. The most important progress has been the inclusion of the category 'Any other' so that anyone in the country who is disabled and her/his disability is not listed as a category can get themselves counted. (Annexure I)

2: Question on disability moved up from number 15 in the last Census to number 9, thereby increasing the probability of the enumerator asking the question.

3: NCPEDP and DRG are now working closely with the Census Commission on the training and sensitization of enumerators and also spreading awareness among persons with disabilities so that they do not shy away from getting themselves counted.

**III: CREATING AWARENESS:**

**Effective use of media:** Media plays a very important role in the success of any advocacy. It helps bring disability issues on the nation's radar screen and to the notice of policy makers, making it difficult for them to be indifferent to disability issues. There have been instances when media has picked up issues and consistently covered them helping our advocacy initiatives to reach their logical conclusions. A few examples:

**i: Access:** When Prof. Stephen Hawking visited India and NCPEDP took up the issue of access, we were faced with indifference from the authorities. But the media took up the issue and consistently covered it, thereby helping in our advocacy bear success.

**ii: Right to Education:** When a path breaking legislation, The Right of Children to Free and Compulsory Education Act was tabled in the Indian Parliament, it excluded many disabilities from its ambit. DRG took up the issue with the relevant authorities. Media played a huge role in highlighting this issue. In fact, leading news channels televised DRG's press conference on this issue live. Eventually, the Prime Minister, Dr. Manmohan Singh and Chairperson of the ruling United Progressive Alliance, Mrs. Sonia Gandhi intervened and an amendment was made to include all disabilities in the historic legislation.

**Dissemination of Information:** NCPEDP and DRG strongly believe that 'Information is Power'. We keep circulating updates on disability issues to all stakeholders – be it persons with disabilities or DPOs or experts.

Awareness about issues pertaining to disability leads to policy-makers taking appropriate action.

The avenues of awareness are manifold: starting from a simple E-mail to surveys, campaigns, workshops, access audits, reports, networking, seminars, online information, posters, partnerships... the list goes on.

NCPEDP also publishes a fortnightly electronic newsletter called Disability News and Information Service ([www.dnis.org](http://www.dnis.org)) that gives the latest updates on the Indian disability sector. This newsletter has more than 3000 subscribers.

#### **IV: BEING A WOODPECKER**

When talking about advocacy, I always underline the importance of what I call 'The Courage of Conviction' - consistency, persistence and patience in making any advocacy initiative successful. You may be a handful of people who take up an issue and it may initially seem an uphill and an almost impossible task. But the key to any successful advocacy is the courage of conviction to continue lobbying for the issue to a point when others start seeing and understanding your point of view. It may take a month, 6 months, a year even but the key is to keep going. To not give up.

This is what I call 'The Woodpecker Theory'. Visualise a tiny little woodpecker against the huge and thick trunk of a tree and imagine that first peck it takes with its beak. It keeps going on and on till eventually the huge trunk gives in and the woodpecker is able to create its nest, its home!

#### **Case Study 1: A Chapter on Disability in the XIth Plan 2007-2012**

Economy of India is based on 'Five Year Plans'. The role of the Five Year Plans is to make assessment of all resources of the country, augmenting deficient resources, formulating plans for the most effective and balanced utilisation of resources and determining priorities. Thus, all schemes and plans of the Government and the resource allocation for the same are done according to the Five Year Plans.

When the XIth Five Year Plan was being drafted, DRG recommended that disability sector leaders and experts should be part of the Steering Committee. There was resistance from the authorities but DRG kept on with its advocacy. Hundreds of disabled people under the banner of DRG held *dharnas* (sit in protest) outside the Planning Commission premises. After one such vigorous '*dharna*', NCPEDP and DRG were invited to participate in the policy development process. Disabled leaders and experts were included in the Steering Committee and for the first time in the history of India, an entire chapter on disability was included in the XIth Five Year Plan. This chapter mandated:

- Setting up of a separate Department on Disability Affairs
- Allocation of 3% of the budget of all Ministries for disability issues
- Setting up of a Sign Language Research Institute

- Setting up of a National Institute on Universal Design, and so on.

### **Case Study 2: A New Disability Law**

Last year, the nodal Ministry on disability decided to go in for amendments to the Disability Act of 1995. India had ratified UNCRPD IN 2007. DRG felt that it was time for India to get a brand new disability law based on the letter and spirit of UNCRPD. DRG met the concerned Minister to discuss this possibility. Our advocacy did not stop at that. A Core Group was formed of Delhi based disability sector leaders and this Core Group started drafting the framework of the proposed new law.

Even as the Ministry continued to dither on the issue, NCPEDP and DRG decided to take this idea across the country and held one National Consultation and 4 Zonal Consultations to build public opinion. The idea of a new law was even met with skepticism from a few people from within the disability sector. But eventually our advocacy was successful when on April 30<sup>th</sup>, 2010 the Ministry formed a Committee to draft a new disability law based on UNCRPD.

DRG also ensured that disabled people were included in this Committee. DRG is now closely monitoring the progress of our idea taking shape.

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