



**MOVING TOWARDS SUPPORTED DECISION MAKING  
– EXPERIMENTS & EXPERIENCES IN INDIA**



**J P GADKARI**

President, PARIVAAR, INDIA

Presented at : **15<sup>th</sup> WORLD CONGRESS  
INCLUSION INTERNATIONAL AT BERLIN**

**June 19, 2010**

**Greeting to all from  
PARIVAAR India !**



## Preamble

- We are here to see and evaluate how the world has moved forward to implement the provisions of the historical, epoch-making United Nations Convention on the Rights of Persons with Disabilities [UNCRPD].

## Preamble....

- We are here to find out how each country which has signed and ratified the Convention has moved forward and made progress towards the intended objective.
- We are all clear in our mind that in order to ensure the rights of persons with disabilities it is essential for us to recognize that every person with disability has the **Legal Capacity** and she or he is **person before the law.**



### Preamble...

I am here to present a short paper on this very important aspect of the UNCRPD as to what has been our experiences in India and what were the legal and other obstacles we encountered while moving forward towards supported decision making for people with intellectual disabilities.

## BASIC FACTS

- India is a country with a population of 1.20 bn --- the second largest in the world after China.
- India has 30 states --- large and small with people speaking different languages, dialects; having different religions, culture, traditions, customs.



- India has an estimated population of 50 to 60 million of people with disabilities.
- Among these 20 to 30 million are people with intellectual and other developmental disabilities.

### UNIQUE FEATURE

- Among the countries of Asia-Pacific region India has the distinction of having a comprehensive law on disability which was enacted in 1995.
- The unique feature of this Act is that it speaks about 'Protection of Rights', 'Equal Opportunities' 'Full Participation' of people with disabilities in all spheres of civil society..



## OTHER LAWS

- Another important legislation is the 'National Trust Act' for fulfilling the special needs, requirements of people with intellectual and other developmental disabilities (IDDs). It was enacted in 1999.
- There are other two disability-related legislations: the Rehabilitation Council of India Act 1992 which regulates the training courses for manpower development and Mental Health Act 1987 which covers mental illness.

- But despite its laudable objectives the 1995 law, the Persons with Disabilities Act is basically a welfare legislation and the 1999 National Trust Act is a service providing legislation.
- While the Persons with Disabilities Act 1995 included intellectual disabilities alongwith other disabilities, it did not provide the services needed for them thus creating space for a separate service providing Act.



## PROCESS OF CHANGE

- After India signed and ratified the UNCRPD in October 2007, these two legislations – P.D. and N.T. Acts came into limelight focusing on the urgent need to review, revise, reframe and making them rights based by harmonizing them with UNCRPD.
- This process is still on and has gained some momentum with the growing pressure from the disability sector on Government of India.

## PARIVAAR --- THE PARENTS' MOVEMENT

- Parivaar is the National Federation of Parents Associations for persons with intellectual and developmental disabilities having more than 200 organizations as its members throughout the country.
- Parivaar meaning family was formed in 1995 initially with only 22 members.



Awareness at local level



## SELF-ADVOCACY

- Self-advocacy movement is new in India but its spirit is catching up. Two years ago Parivaar took initiative in forming the Self-Advocates Society of India under the auspices of Parivaar and it has branches in several states now. Two self-advocates are the members of Parivaar's National Executive Council.



## LEGAL CAPACITY & SDM

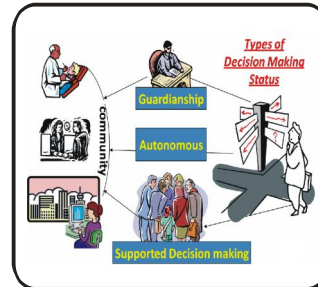
- Parivaar has the distinction and honour of implementing Article 12 of UNCRPD demonstrating a model of Supported Decision Making enabling them to have access to a support network.
- This project is being supported by Inclusion International, Disability Rights Fund [DRF] with partnership with National Trust and National Institute for the Mentally Handicapped [NIMH] – the two autonomous bodies under the direct control of the Ministry of Social Justice and Empowerment, Government of India.





## LEGAL GUARDIANSHIP

- Though Parivaar pilot projects have been making positive headway, it has been found very difficult to convince parents of IDD's to accept the alternative to Legal Guardianship.
- The experience that Parivaar gained shows that parents of IDD's are not easily amenable to the idea of Supported Decision Making [SDM] as they were provided with the shield of Legal Guardianship under the National Trust Act.



- It is somewhat difficult to veer them away in favour of SDM as the provision of Legal Guardianship under the provisions of N.T. Act is still easily available to them and the alternative is still not in place.
- The self-advocates however are more positive and forthcoming. They want to take their own decisions. They are unhappy about their parents imposing decisions on them.



- Parivaar firmly believes that Article 12 is the heart of UNCRPD and only through this alternative all rights enshrined in the Convention can be ensured.
- It may be a long way but if this basic fact is accepted by people with disabilities and the civil society, everything will fall in place.



**THANK YOU**