# Disability as a Human Right Issue: India's Invisible minority in the policy Realm

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#### INTRODUCTION

The world Report on Disability published by the world Health Organization (WHO) and the World Bank says that 15 percent of the world's population or 1 billion people live with a disability. If we go by the 15 percent figure, India should be home to more than 150 million people with disabilities! Even if we take a conservative 7-10 percent, India is home to at least 70-100 million people with disabilities. This is a huge a section of our population. And yet, we hardly see them in the mainstream. But this doesn't mean that these millions are not there, among us. It is just that we as a country have neglected to include them in the mainstream.

Another reason, equally important to note is that the concept of disability rights as a movement in India is still very young.

Cross-disability movement in India! Disability organisations in India have been in existence for many decades, some for more than 50 years or so. Yet the concept of disability issues as rights was alien till as late as the 90's. It was only in 1993, with the creation of Disabled Rights Group (GRG), India's first cross-disability advocacy organisation, that the idea of "all rights of all people with disabilities gained currently. The words handicapped", "disabled", "differently abled', 'retarded" have various meanings and carry the potential for prejudicial stereotypes, discrimination and abusé. Dusability may relate to body or mind. Also disability can be of a short term or long term nature. Some disabilities may be of permanent nature.

The most acceptable and dynamic definition of disability is proved in the UN Convention on Rights of persons with Disabilities (UNCRPD) Which states that" persons with Disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

Disability is an umbrella term for impairments, activity limitations and participation restrictions' which cause by an interaction between the health conditions of an individual and the contextual factors reflected in the social-economic environment of the day. The understanding about disability has moved away from a biological perspective to questions of accessibility, inclusion and empowerment.

Care and consideration for the sick, elderly and disabled has always been a part of Indian culture and tradition. However, in earlier times, disability was considered as a punishment for acts committed in earlier lives, and the attitude towards persons with disabilities (pwDs) has been one of charity. It is now being accepted that the major cause for disabilities is deficiencies in the management of the environment in which we live and that if we manage the environment better, then disabilities can be reduced.

Art 41 of Indian constitution deals with the issue of disability in the context of right to work and education. The government has also moved away from the welfare oriented policies on disability towards a rights based approach.

#### CROSS-DISABILITY MOVEMENT IN INDIA

Disability organizations in India have been in existence for many decades, some for more than 50 years or so. Yet the concept of disability issues as rights was alien till as late as the 90's. It was only in 1993, with the creation of Disabled Rights Group (DRG), India's first cross-disability advocacy organization, that the idea of 'all rights of all people with disabilities' gained currently.

Disability Act of 1995: The first thing the DRG realized was the absence of a law that ensured the rights of people with disabilities, which otherwise are available to any other citizen of the country. This was after nearly half a century after independence. So during the crucial years of nation building our schools,

colleges and universities, our roads and public infrastructure etc, people with disabilities were left out to remain in the confines of their homes-with no future, no dignity and no rights.

After an intense advocacy campaign by DRG, the Disability Law of 1995 was finally enacted. This forms the basis of whatever little advances India has been able to make in the area of disability, even today. Enumerating the 'invisible minority": When DRG started its advocacy with the Government for a disability rights law, it realized that India never considered enumerating people with disabilities. India's census operation dates back to the British era 1972 and has been conducted uninterruptedly every 10 years. What is even more surprising is that till before independence, a question on disability, though very crude, was always asked. This was then dropped in census after Independence and was included in 1981, which was the International year for Disabled people. However, it was again dropped in the census of 1991. In 1999, DRG wrote to the Government to include disability in the 2011 census. To our utter dismay, this refused. This followed a vigorous campaign that went on for several months, where people with disabilities had to come out on the streets to protest. Eventually and at the very last moment a question on disability was hurriedly included. It was not a well- framed question and left several disabilities out, and there was no sensitization of enumerations did not even ask the question. Nevertheless, the Census data revealed that India was home to 21 million people with disabilities, or 2.1 percent of its population. The 11th Five year plan document admits that this was an underestimation and states, "It can be reasonably assumed that persons with disabilities constitute anywhere between 5 to 6 percent of our total population".

The next challenge was to get a more accurate enumeration of disability in the 2011 Census. National Centre for Promotion of Employment for Disabled people (NCPEDP) and the National Disability Network (NDN) led a campaign in 2010 for improving the question on disability, prioritizing the question on disability and making disability an integral part of the training and sensitization programme of the enumerators in the Census of 2011. This time the Census Commission was also more sensitized and aware and with their support all of this could be achieved. It is now hoped that when the disability data

under Census 2011is revealed, it will show a substantial increase over last time.

## DISABILITY IN THE FIVE YEAR PLAN

As is well known, the Five year plans set the tone for the development agenda and resource allocation for the nation. The extent to which disability was neglected in the policy realm can be gauged by the fact that for as long as the 10th plan, there was almost no mention of disability whatsoever. During the formulation of the 11 plan DRG led a huge campaign for substantial Inclusion of disability and for recognizing the fact that it is a cross- cutting human rights issue. Again after protracted advocacy that saw people with disability come out on the streets, disability found a significant mention in the chapter on 'social justice'.

The 11 Plan mandated a firm four-pronged approach to mainstream disability:

- 1. Delineate clear-cut responsibilities between the concerned Ministries/ Departments.
- 2. Concerned Ministries/ Departments to formulate detailed rules and guidelines within six months of approval of the eleventh plan.
- 3. Ensure that each concerned Ministry / Department shall reserve not less than 3 percent of their annual outlay for the benefit of disabled persons as enjoined in the persons with Disabilities Act 1995.
- Set up monitoring mechanisms at various levels and develop a review system so that its progress can be monitored on a regular and continuing basis.

It is because of the 11th Five year plan that we now have a Department of Disability Affairs and the Indian Sign Language Research and Training Centre (ISLRTC).

### DISABILITY IN THE 12TH FIVE YEAR PLAN

Though the 11 plan had a very substantial mention of disability, its implementation was extremely abysmal. The primary reason for the poor implementation was the fact that although disability was mentioned as a cross- cutting issue with clear mandated for several Ministries, the concerned section was hidden away as a part of the larger chapter on social justice. The result was that when NCPEDP filed Right to Information

# © September 2023 | IJIRT | Volume 10 Issue 4 | ISSN: 2349-6002

(RTI) applications with some 20 Ministries in 2010-11, none of the Ministries or Departments were even aware of the section on disability in the 11 plan. They did not have any Disability policy nor any budget for disability issues.

Learning from this experience, it was essential that in the 12th plan disability was included in all relevant chapters of the document. In 2011, when the planning commission was setting up steering committees to formulate the 12th plan, NCPEDP and DRG advocated for the inclusion of people with disabilities and disability experts in all relevant committees in addition to the steering committee on disability. And for the, first time in the history of the nation, people with disabilities and experts were made part of the steering committee on Labour, Transport, Health, Women and Child Rights, Housing & Poverty Alleviation, Science & Technology, youth literacy and so on. It was hoped that with this all relevant chapters would have adequate mention of disability. Unfortunately, the 12 plan document that was unveiled recently did not quite reflect this. In fact it seems that the 11th plan had a much more rights based approach towards disability and had more for people with disabilities than the 12th plan.

#### CRPD AND A NEW PARADIGM IN DISABILITY

The Convention on the Rights of persons with Disabilities (CRPD) is the first human rights treaty of the 21" century. It is also the fastest negotiated human rights treaty. It saw a record number of signatures on the opening day itself.

CRPD underlined the need to look at the human rights of people with disabilities who comprise some of the poorest and most vulnerable section of society. It firmly established disability as a cross-cutting human rights issue. It brought in a new progressive paradigm especially for those disabilities that have so far been neglected and marginalized.

In 2006, NCPEDP and DRG led a campaign for speedy ratification of CRPD by India. Finally, when all advocacies seemed to yield no result, convener of DRG announced an indefinite hunger strike from Oct 2, 2007(Gandhi Jayanti). It was a happy coincidence that the Government ratified the convention on Oct 1, 2007 by doing so; India became the 7th country in the world to ratify CRPD, ahead of some of the other

much more progressive nations in terms of disability rights.

#### INDIA POST CRPD

When India ratified CRPD, it made a commitment to its people with disabilities to its people with disabilities and the international community to protect fulfills and promotes all rights of all people with disabilities.

It fact, the 11 Five year plan recognizes this and states, "India being a signatory of UNCRPD it is now obligatory upon us to incorporate the essence of the Convention in our planning, implementation, monitoring, and review processes." It also mentioned the general principles of CRPD and stated, "There is an urgent need to review all the four disability legislations and to amend them suitably to bring them in consonance with UNCRPD".

In 2009 when a new social justice minister took over, the government decided to amend the 1995 law. When NCPEDP and DRG looked at the proposed amendments, they realized that even with 100 plus amendments, the 1995 law would never truly reflect CRPD. The problem lay at the very core of the 1995 law-the fact that it was ridden with charity, and no amount of amendments would be able to change that. DRG then proposed that it was time for a new disability rights law that would reflect the letter and spirit of CRPD. After a year of advocacy, the government constituted a committee in April 2010 to draft a comprehensive disability rights law in consonance with CRPD.